THE INFLUENCE OF PATIENT-CENTREDNESS DURING GOAL-SETTING IN STROKE REHABILITATION.

BY

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ABSTRACT

Background: Guidelines suggest that rehabilitation for people with stroke should adopt patient-centred goal-setting (PCGS).

Methods: A literature review and two qualitative studies were done in an acute stroke-unit. Study one aimed to explore influence of PCGS within stroke rehabilitation. Patients with stroke, with ability to participate and staff caring for them were included. Data collection involved interviews, observations, document analysis and focus-groups. Analysis involved sequential and intra-case analysis methods.

Study two aimed to build a resource to improve PCGS and evaluate its feasibility and appropriateness. Based on Study one and review, a resource (T-PEGS) was developed and applied in this setting. Patients with same criteria as Study one and staff who agreed to act as keyworkers were recruited. Data collection and analysis methods were similar to Study one.

Findings: Study one, with thirteen patients and twelve professionals, revealed limited application of PCGS due to participants' health beliefs, limitations in knowledge and resources. Study two involved five patients and five staff who applied T-PEGS; recording of psychosocial goals, information sharing and rapport between patients and professionals had improved.

Conclusion: T-PEGS seemed to improve PCGS locally. Small study-size and single site limit generalisability. Future work should explore mechanisms and effectiveness of T-PEGS.

DEDICATION

To my late father Mr. Rosewilliam who instilled in me the value of education and my mother who supports me in everything I do.

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First and foremost, I would like to thank the patients (and in some cases their families) who participated in this research despite their difficult situations and so willingly shared their views, feelings and friendship during their participation. I would like to thank the clinicians in the NHS who gave of their valuable time to contribute their views and for taking efforts to try a new process. I would also like to thank the therapists, the consultants and researchers on the wards for their support and feedback at various points during the research. I would like to extend my special thanks to Mrs. Carron Sintler who was the PI for this research who helped to run the study and for her contribution to dissemination of the work.

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PREFACE TO RESEARCH

This reflexive account is set out to enable readers to understand the influence of the researcher's (my) beliefs, background, culture and life experience on decisions made during the research process and interpretation of its findings. I have attempted to be honest in this account to make explicit my beliefs that could have influenced or biased the reported findings. However, measures to counteract such reactivity and biases were taken, and are described in the methodology and discussion chapter.

I was trained as a physiotherapist in an ethical and spiritually-grounded institution that trained multidisciplinary health professionals in small groups (Christian Medical College-India). This might have been the foundation for me being attracted to a concept that is ethical within the context of multidisciplinary working. However growing up in an Asian culture where doctors are considered as Gods (even the poorly patient stands up as a sign of respect when the doctor walks into the patients' waiting area), gave me a sense of awe at the patient-centred guidance given to the clinician working in the West. Yet, I wondered whether this is possible. Moving into academia made me more critical of practice and how it does not align with the guidance; but I had a yearning to reform practice.

The academic position was advantageous in the process of data collection as an outsider, but, gaining trust of professionals required prolonged hours of staying on the ward, feeling helpless and useless in a busy environment. However this 'hanging around' (getting to know people) helped me not to be a 'professional basher', even though as an academic I could see the chasm between theory and practice. Patients trusted an outsider and were forthright in their interviews which swayed me, as a person, towards their views. Again my tendency to lean too much towards the views of patients (in line with the philosophy of this work) was

moderated by the involvement of clinicians but also by consciously adopting a reflexive approach during analysis and interpretation. The involvement of the clinical lead physiotherapist in this research and moderation of my assumptions by supervisors in monthly meetings helped me to be critical, yet, balanced in my interpretations. Further writing up this work for publications and panel reviews along the way moulded my way of thinking to be more flexible. I felt privileged to be involved in the local stroke team to help out with the structuring of a document based on the International Classification of Functioning, Disability and Health (ICF). This document integrated assessments across disciplines and was created following feedback after the first study. Better still there was a sense of achievement when, during feedback on the second study, I was informed that certain strategies had been adopted from this work, for goal-setting with complex patients in routine practice.

I realise that I am not an abstract thinker, but more of a pragmatist; hence my critical realist stance led to attempts to change practice rather than attempts to build substantial theory. I identified from my own practice and knowledge of the literature that goal-setting processes needed development in the area of stroke rehabilitation, being a good forum to incorporate patient-centred working within this area. Hence the first stage of this work was to explore local practice and integrate findings from my systematic literature review to build a process (resource) for patient-centred goal-setting. Piloting followed within the facility where it was developed to promote change from within. Following on from this work, future research has been set up to examine the usefulness of this resource and answer the many questions (discussed in the final chapter) arising out this work.

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GLOSSARY

Multi-Disciplinary Team (MDT) - A model of team working, where professionals work within the scope of their disciplines, to set goals and treat patients, with minimal collaboration with professionals from other disciplines.

Goal-setting (GS) - It is defined as a formal process by which, rehabilitation professional or team negotiate goals with patient and or family.

Patient-centred care (PCC) - Variably defined in literature; an integrated definition of PCC by Morgan and Yoder (2012, p.8) is that "it is a holistic (bio-psychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care."

ABBREVIATIONS

PCGS- Patient-Centred Goal-Setting

MDT- Multidisciplinary Team

QoL- Quality of Life

KW- Keyworker

PCC- Patient Centred Care

NHS- National Health Service

CHAPTER 1

INTRODUCTION

1.0 Overview of chapter

Goal-setting for rehabilitation of patients with stroke, embedded within the philosophy of patient-centredness, is the focus of this research. Pathology, diagnosis and clinical management of stroke are aspects not directly relevant; however an overview of prevalence and manifestation of stroke, which will establish the need for the study, is offered. The process of rehabilitation encompasses a wide portfolio of processes such as assessment, setting goals, delivering interventions, secondary prevention, discharge planning and follow up care; but in this chapter, the focus is restricted to a critical discussion of the process of goal-setting, the working of the healthcare team within the process, leading on to the issues in the current approaches to goal-setting. This paves the way for the discussion relevant to a proposal for patient-centred approach to goal-setting - the focus of this study.

1.1 Background

1.1.1 Global burden of stroke.

Stroke, otherwise known as cerebrovascular accident, is caused due to pathologies arising from blood clots or bleeds in the blood supply of the brain (World Health Organization (WHO), 2011). Stroke is the third major cause of death and third leading cause of disability adjusted life years (DALY) in the world (Lozano *et al.*, 2012; Murray *et al.*, 2012). Globally,

five million survivors out of the 15 million people who have stroke annually are left with disabilities (WHO, 2011). Though stroke mortality and mortality-to-incidence ratios have decreased in the years from 1990-2010 (Feigin *et al.*, 2014), the global burden of stroke has increased due to rise in the absolute numbers of stroke, survivors, and DALYs lost. In low and middle income countries, the high prevalence of stroke is due to an increase in risk factors and inadequate management of the risk of stroke (Krishnamurthi *et al.*, 2013). Whereas, in high income countries, despite a lower incidence, the prevalence is still high due to an ageing population and lower mortality-to-incidence rates attributed to better access to healthcare and management of acute stroke. Consequently, the numbers of people left with a disability from stroke and requiring rehabilitation has increased.

Specifically, in the UK, where, though the incidence fell by 30% and mortality by 12%, due to better drug management in primary care services, the prevalence has still risen by 12.5% (Lee, Shafe and Cowie, 2011).This translates to a financial burden on the state which incurs the costs of care, lost productivity and informal care, estimated at eight billion pounds per year (Saka, McGuire and Wolfe, 2009; National Audit Office (NAO), 2010). It is necessary that this burden from increasing prevalence and the subsequent financial implications be countered through healthcare systems that deliver efficient and effective processes of care.

1.1.2 Personal burden of stroke

Stroke results in destruction of brain tissue which could lead to loss of control of functions such as movement, sensation, speech, swallow, cognition and respiration. The effect of this pathology, situated within the survivor's unique environmental, social and psychological

context, contributes to the personal burden for a stroke survivor and his/her immediate family (Stroke Alliance for Europe (SAFE), 2007), as will be discussed briefly in this section.

Primarily, the personal burden which follows from a loss of motor function is the most commonly identified consequence of stroke (Hafsteinsdóttir and Grypdonck, 1997; Lawrence *et al.*, 2001). This leads to a further burden from loss of independence in mobility, limitations on the activities of daily living, and functional ability. Moreover cognitive problems (confusion and memory loss) and sensory problems such as visual and perceptual deficits exacerbate these issues. These sensory-motor and cognitive issues that result from the brain pathology are routinely picked up in the clinical assessments and hence are catered for. Contrarily, psychological consequences such as apathy, anxiety, irritability, aggression, mania and emotional lability (Robinson, 1997; Gunnel, Anders and Christian, 2009) can occur secondary to the physical issues or due to pathology itself, and are seldom identified (Stroke Association, 2013). Critically, these emotional burdens persist in the long-term, with patients seeking support from healthcare providers for shock, fear, loss of control, frustration and depression (Hafsteinsdóttir and Grypdonck, 1997; Murray *et al.*, 2003; Hare *et al.*, 2006).

Within the wider context of a person's life, social functioning involving employment, leisure, social relations and participation in events are often reported to be affected in the long-term (Teasdale and Engberg, 2005). The subsequent financial issues, altered dynamics within the family and breakdown of relationships (including sexual relationships) further worsens the burden for stroke survivors (Daniel *et al.*, 2009). Most often a person's burden from stroke is not the result of a single sequela; rather, there is a complex interaction of consequences ultimately affecting the overall quality of life (QoL).

QoL indicates the unique personal perception and reaction of the patients to, not just health, but other non-medical aspects of their life (Gill, 1995). QoL is largely determined in stroke patients by psychological factors (anxiety and depression) (Jönsson *et al.*, 2005; Raju, Sarma and Pandian, 2010), physical function (weakness and upper limb deficits) (Nichols-Larsen *et al.*, 2005; Raju, Sarma and Pandian, 2010), cognition (Baumann *et al.*, 2014) and communication (Nichols-Larsen *et al.*, 2005). Interestingly, the level of physical deficits does not seem to determine the levels of psychological distress or the QoL (Hackett *et al.*, 2000; Samsa and Matchar, 2004). Rather, limitations in social functioning and limited social support leading to social isolation have consistently been shown to influence QoL (Haley *et al.*, 2011; Baumann *et al.*, 2014). Despite the importance of the psychosocial consequences of stroke on the wellbeing of the patient, these are often inadequately assessed (Stroke Association, 2013). Even the well-established QoL assessments such as SF 36 might not be sensitive to identify psychosocial issues relevant to stroke (Hackett *et al.*, 2000). Thus there is a further need for holistic approaches to understand patients' needs, care and wellbeing following stroke.

A stroke survivor's burden extends to the immediate carer and family. Care-givers have high rates of depression, anxiety, and ill-health resulting in poor socialisation, quality of life and in extreme situations higher mortality rates (Rigby, Gubitz and Phillips, 2009). Ultimately, this effect on care-givers' health, is detrimental to the patients' recovery (Glass *et al.*, 1993) potentially institutionalising them.

Based on the above discussion, rehabilitation processes for stroke should consider the fact that each stroke survivor presents with unique and complex sequelae. Hence, rehabilitation requires an individualistic and multifaceted approach for optimal management, with a primary focus on the survivor himself, who bears the major burden of stroke.

1.2. Delivery of stroke care

Stroke care is a long term process requiring various interventions at different stages, from hyper-acute to community-living or a palliative stage if patients fail to recover. In every stage, rehabilitation as an 'active problem-solving and educational process' should be delivered by the health professionals to reduce the burden of disability and enable the patient's integration in the community (Wade and de Jong, 2000, p.1386). Though rehabilitation involves multiple processes of assessment, goal-setting, intervention and reassessment (Wade and de Jong, 2000; Brewer *et al.*, 2013), this section will focus merely on the rehabilitation context and the multi-disciplinary team (MDT) working pertinent to goal-setting, the focus of this study.

In the early stages of recovery it is recommended that stroke rehabilitation is delivered by a specialist team of health professionals working together in multi or interdisciplinary teams (Duncan *et al.*, 2005; Lindsay *et al.*, 2010; National Institute for Health and Care Excellence (NICE), 2013). These teams care for a patient within an inpatient facility, rehabilitation facility, in the outpatient-department or in the community, once the patient achieves medical stability. There is some evidence that these different systems for provision of stroke care are effective in achieving better outcomes. For example, care by well-coordinated and trained multidisciplinary teams in designated stroke units has been shown to improve outcomes such as survival rates and living independently at home a year after their stroke (Stroke Unit Trialists' Collaboration, (SUTC) 1997; Strasser *et al.*, 2005). Another example in the community, the early supported discharge system which provides multi-disciplinary rehabilitation at home, has been shown to reduce dependency in the long term (Laver *et al.*, 2014). It should be noted that the commonality in these different care systems is the co-

ordinated multidisciplinary teamwork which has consistently been shown to have good outcomes in independent living (SUTC, 2007; Laver *et al.*, 2014).

The multidisciplinary teams consist of medical, nursing, rehabilitation staff and social workers trained to deliver care to stroke patients (Intercollegiate Stroke Working Party, (ISWP) 2012). These professionals should routinely coordinate care through regular planning meetings which provide them with a sense of direction and common motivation. This process of planning should involve goal-setting for rehabilitation and reviewing goals at regular intervals (Wade and de Jong, 2000). It is thought that goal-setting could enhance team cohesion and ultimately benefit patient outcomes through co-ordinated rehabilitation efforts for the recovery of the patient (Levack *et al.*, 2006a). However, if team working fails, there is the possibility of fragmentation of care (Schwamm *et al.*, 2005) resulting in negative experience and outcomes for the patient.

1.3. Goals and goal-setting in rehabilitation

Goal-setting is a process during which plans are developed to facilitate the achievement of desired outcomes in various fields including education, business, sports, industry and increasingly, in healthcare. Within healthcare, goal-setting has been described as a foundational stone for rehabilitation of patients (Levack *et al.*, 2006b; Scobbie, Wyke and Dixon, 2009; Wade, 2009). The ultimate aim of rehabilitation following stroke is to maximise the potential of a person for better social participation and quality of life, and to reduce stress on carers (ISWP 2012). In order to realise the aims of rehabilitation, the current and prior status of the person needs to be assessed. Thus the goal-setting process can be considered as

making links between the patient's status prior to stroke, current abilities and rehabilitation potential (inferred from assessments), and future aspirations such as social participation. However, aspirations for an altered state such as independence or social participation require behavioural change that directs effort towards these aspirations. Therefore goal-setting or goal planning can also be defined as the process for the 'identification of and agreement on behavioural targets which the patient, therapist or team will work towards, over a specified period of time' (ISWP 2012, p.31).

Wade defined a 'goal' as a more favourable state towards which 'a person's behaviour is consciously or unconsciously directed' (Wade, 2009, p. 291). In order to achieve behavioural changes, the goals set should be relevant to the person whether they are assigned, set collaboratively, or self-set (Locke and Latham, 2006). Ultimately, "the content of a goal is what the person is seeking" (Locke, 1996, p. 118). Thus in the present context, we can think of goals as personal targets for patients, set collaboratively by a patient with his or her family/friends and the MDT, within a rehabilitation context (Levack *et al.*, 2006a; Wade, 2009). Failing this collaboration with patients, professionals set goals which tend to be merely their 'plan of action' (Playford *et al.*, 2000) and thus a set of behavioural targets imposed by professionals, which are not necessarily congruent with the patient's wishes (Wressle, Oberg and Henriksson, 1999; Bendz, 2003). This could lead to a lack of motivation and attention and limit effort and action towards achievement of goals (Locke and Latham, 2006). To avoid this incongruence, goal-setting should represent a framework of collaboration to guide negotiation for planning/management of rehabilitation (Wade, 2009).

1.4 Goal-setting in stroke rehabilitation

Healthcare policies arising from political and government directives and national guidelines based on existing evidence, play a major role in shaping healthcare delivery. For example the Department of Health (DoH) frameworks, reports and policies issued by the UK government (DoH, 2001; DoH, 2005; Darzi, 2008) advocate increased patient involvement in all healthcare processes, co-ordinated delivery of healthcare by different professionals and improved quality and experience of care. Additionally, the recent Royal College of Physicians (RCP) guideline for stroke (ISWP, 2012) strongly recommends patient involvement in the goal-setting process. These directives are followed up via regular audits of professional practice. Yet, failure to co-ordinate care, involve patients in decision making and deliver high quality care is widely prevalent in many National Health Service (NHS) trusts (Francis, 2013; Keogh, 2013). If gaps in quality and experience of care are prevalent, it is appropriate to examine the role of existing processes within healthcare systems, such as goal-setting, to involve patients, co-ordinate delivery of MDT care and improve quality of care.

The RCP guideline for goal-setting in stroke is based substantially on consensus, given the limited research in this area (ISWP, 2012, p.32). Despite this obvious limitation of inadequate research in stroke-specific settings or stroke populations, there is still a need to understand the process including the theory underpinning goal-setting, the constructs involved, the purposes for goal-setting, proposed mechanisms of how it works, and methods. The literature in neurorehabilitation including patients with stroke as part of a wider patient cohort offers the best starting point for this wider understanding of the process. Hence the neurorehabilitation and available stroke-specific literature were analysed initially to inform the background and to gain understanding of the wider context of goal-setting (Rosewilliam, Pandyan and Roskell,

2014). Key aspects of this theory which includes the purposes and mechanisms of goal-setting is presented in appendix 1.1.

1.5 Need for better goal-setting methods

Firstly, due to the chronic yet non-progressive nature of the pathology of stroke, the experience of goal-setting in stroke rehabilitation is different from other neurological conditions (Van De Weyer, Ballinger and Playford, 2010). Moreover, stroke care is a speciality in which trained professionals carry out goal-setting as one of their key responsibilities (Management of Stroke Rehabilitation Working Group, 2010; Albert and Kesselring, 2012); they require methods specific to their system and patient population.

Secondly, the goal-setting studies seemed to concentrate on the sub-acute stage of rehabilitation where recovery potential is optimal due to the medical stability of patients; moreover, this is the period of natural neurological recovery (due to neuroplasticity). There were a few studies done with chronic stroke survivors in the community (Combs et al., 2010, Deutsch et al., 2012) and in outpatient departments (Rotenberg-Shpigelman et al., 2012), but, the acute stage of stroke rehabilitation has been largely ignored. This is probably because most bio-medical research focuses on the medical management of the patient with the aim of achieving medical stability during the acute stage. Additionally, clinicians and patients suggest that patients might not be ready to set goals at this stage due to being in shock (Laver *et al.*, 2010). Despite this, it is recommended that stroke rehabilitation should start early after stroke, to improve outcomes (Cumming *et al.*, 2011). There is also a professional requirement for clinicians to set goals for patients within five days of admission which is regularly audited

across all stroke units in UK NHS trusts (ISWP, 2011). Further, the increasing push towards early supported discharge to enable patients to go home early with rehabilitation and support packages (Laver *et al.*, 2014) also means that goal-setting should be carried out early. Thus there is a clear necessity for further research and development in this area.

Thirdly, though not specific to the acute stage, some approaches and methods for goal-setting described have been evaluated empirically (the Rivermead rehabilitation centre method (Elsworth *et al.*, 1999) and Holliday *et al*., (2007) method) and have been found to be effective. However, the only national survey of rehabilitation professionals regarding goal-setting practice revealed that the use of structured goal-setting methods by clinicians for patients was minimal (only 5%) (Holliday, Antoun and Playford, 2005). Use of these structured methods might have been limited to specialised centres where studies were undertaken since there is no further documented evidence for the use of such structured methods. Moreover, the lack of structured methods has been suggested as a possible reason for professionals finding goal-setting challenging (Sugavanam *et al.*, 2012). This reflects a need for clinicians to be trained to improve their knowledge and skills in implementing goal-setting and evaluating its outcomes. However, training of professionals for goal-setting is still problematic as the two latest reviews in stroke rehabilitation (Kamioka *et al.*, 2009; Sugavanam *et al.*, 2012) reveal that there is no method of goal-setting specific to stroke rehabilitation. Even the latest stroke guideline (ISWP, 2012) gives only a sparse outline of a framework for goal-setting, with no suggested steps or tools for the process.

Finally, in-depth studies of the goal-setting process revealed several issues related to the patient's role within current practices. In a Swedish study, patients set goals for rehabilitation that were contextualised in their lives prior to stroke, the life roles they fulfilled at that time,

and their fear and insecurity (Wressle, Oberg and Henriksson, 1999). Therapists and medical professionals, on the other hand, contextualised goals in terms of mobility, the activities of daily living, personal care and appropriate home adaptations (Bendz, 2003). This implies a difference in expectation of recovery between patients and professionals which was not reconciled because the goal-setting happened without patient involvement (Suddick and De Souza, 2006). Moreover professionals discussed motivation as a prerequisite for participation in rehabilitation (Maclean *et al.*, 2002); yet, without involvement and lacking personally relevant goals, it is difficult for the patients to be motivated (Deci and Ryan, 2000).

To summarise, non-involvement of patients results in a lack of awareness of their needs. This means their goals are not prioritised, they suffer a lack of empowerment, and this in turn defeats the purposes of goal-setting which are to motivate, to improve participation, autonomy, effort and goal commitment (Rosewilliam, Pandyan and Roskell, 2014) potentially affecting outcomes. And yet, most studies did not include goal-setting methods that enabled patient participation, and therefore the role of patient participation in improving patient performance and outcomes is not clear in the stroke population.

Following on from the definition of goal-setting as being aimed at a change of behaviour towards an altered status, this aspired status (i.e. goals) should be relevant and personally meaningful to the patient for reasons discussed above. Therefore, if goal-setting can be focused on the patient, based on a 'patient-centred' approach, then the chances of personalised rehabilitation may be improved. This brings us to the concept of 'patient-centredness' itself.

1.6 Patient-centredness in healthcare: evolution, drivers, definitions and principles.

The concept of patient-centeredness in care (PCC) has been extensively quoted in literature (Morgan and Yoder, 2012) and widely recommended as an indicator of care quality (Coulter, 2002; Epstein and Street, 2011). However, multiple synonyms for the term patient-centredness such as patient-orientated, person-centredness, client-centredness and client focused with different intended meanings have been used, apparently more or less interchangeably. Consequently, its interpretation and application has been variable. The existence of multiple synonyms is perhaps due to its diverse origins in various health disciplines (Leplege *et al.*, 2007) which will be briefly discussed below.

The patient-centred approach to care has been around since the 1940s (Dalley, 1999; Leplege *et al.*, 2007), assuming various forms. For example, client-centredness, used in psychotherapy was an approach based on humanistic psychology (Rogers, 1946) in order to challenge the psychoanalytic approach in which the analyst was dominant. Carl Rogers, a psychotherapist, advocated considering a patient as a person who has the human tendency to fulfil one's own potential. He regarded patients as experts in their own life and hence suggested that providing optimal conditions can enable them to identify their own needs and problem solve. The conditions he proposes are embedded within the 'therapeutic relationship' and include empathy, unconditional positive regard and genuineness on the part of the therapist. This sensitivity to human potential and focus on establishing a therapeutic relationship are aspects that are still considered vital in contemporary consultation models (Mehay *et al.*, 2012) and are key tenets of the PCC approach.

Similarly, Michael Balint, a psychoanalyst working in the 50s, started advocating a shift from illness-orientated medicine to patient-orientated medicine and coined the term patient-centred medicine (Balint, 1969; Duggan *et al.*, 2006). He advocated that general practitioners should understand patients as 'unique human beings' and not as cases or conditions, in order to see beyond the traditional diagnosis and gain knowledge about the whole person (Balint 1969). Balint's approach is still used to train physicians to enable them to analyse their interactions with patients, focused on the therapeutic relationship rather than on their medical condition (Mehay *et al.*, 2012).

In the 1970s George Engel, a psychiatrist, recommended a shift from the doctor-centred bio-medical model which focused on a person's pathology, to a Bio-Psycho-Social model (BPSM) which focuses on the person as a whole, taking into consideration the psychosocial, cultural and environmental aspects of the person (Engel, 1977). He recommended this shift to replace the fragmented and reductionist biomedical approach that was ineffective in explaining patients' experience of illness or modifying it. Despite the BPSM being critiqued for lack of a structure or the definitive concepts that scientific models normally have (McLaren, 1998), it is widely recommended and adopted in health policy, education and practice. For example, the WHO has published the International Classification of Functioning, Disability and Health (ICF), a structure for evaluation of health conditions which requires understanding of the patient's psychological, social and contextual factors (WHO, 2002). This holistic approach to diagnosis and treatment requires an understanding of the patient's experience of illness which is vital to PCC.

Moreover, in the field of disability and rehabilitation, it can be said that a shift towards a patient-centred approach was in large part a societal drive, in order to gain respect and

independent living for people with disabilities. A social movement to integrate people with disabilities into mainstream society and eradicate stigma around disability gained momentum in the 70s, when the Chronically Sick and Disabled Persons Act 1970 and the Rehabilitation act of 1973 were passed. These laws, along with the Human Rights Act 1998 , ensure that public services, such as healthcare services, treat people with dignity, equality and fairness and are accountable to the service user. Thus the legal drive complements the societal move towards adoption of a patient-centred approach.

There is also a cultural and a political dimension to the issue, though it is poorly defined. In general, humans are considered above all as capable of thought and reasoning, and thus having the potential to make choices (Maslow 1943). The choices each individual makes are dominated by the value of 'free will'. This is a cultural norm, certainly within the UK, and therefore a determinant of individual behaviour. Accordingly, people favour freedom for making decisions and choose behaviours relevant to independence in functioning. The healthcare systems that function within such cultural norms also need to ascribe to these democratic principles, for which a patient-centred approach seems appropriate (Saha, Beach and Cooper, 2008). This principle of respect for autonomy is embedded within the professional codes and conduct for healthcare professionals, which draw upon the medical ethics for practice. For example, in the allied health professions, client-centredness is used as a framework to guide occupational therapy practice (World Federation of Occupational Therapists (WFOT), 2010) and physiotherapists are expected to practise in a patient-centred manner (The Chartered Society of Physiotherapy, 2010).

Despite the above drivers supporting a patient-centred approach to healthcare, adopting patient-centred policies is not without challenges (Coulter, 2002). For example, in the

nineties, when the UK government set out plans to offer more choices and 'people-centred' services, these policies (DoH, 1991) were compared to the tenets of consumerism (Williams and Grant, 1998). They questioned whether people with illness can aggressively seek out choices and pursue them or whether these choices become an additional burden. Two decades on, these arguments are still valid following the passing of the Health and Social Care Act, 2012 which offers more choices for patients (consumerist principle). Patients as consumers may not be able to identify alternative choices of health services that are relevant to their needs. Going to different service providers for different health needs (even if they are available within a geographical area) can make care fragmented. Hence a patient-centred approach, when operationalised within the framework of consumerism, might not be useful unless there is clarity regarding the principles of PCC in policy.

Failure in healthcare delivery has in the past led to inquiries such as the Bristol inquiry (Kennedy, 2001) and more recently the Mid Staffordshire trust inquiry (Francis, 2013), the findings of which have highlighted the need for better quality of care in the NHS. The media frenzy following these inquiries has led to the UK government's healthcare policies to prioritise a patient-centred approach to care and improve accountability of the NHS (Darzi, 2008; DoH, 2010; DoH, 2013). These documents advocate that health services must treat people as individuals to enable them to make choices about their own care. This is the principle of empowerment which has also been incorporated in frameworks and guidelines that serve as directives for profession-specific standards (Health and Care Professions Council (HCPC), 2012; ISWP 2012, Royal College of Nursing (RCN), 2010); this makes PCC a professional requirement in practice (DoH, 2001; DoH, 2005). Though the government's response to failures in the NHS emerges from a political agenda, they also reflect the public's

expectation for a better healthcare service. However, similar to most policies, patient-centred policies were not built on scientific evidence thus making their operationalisation, implementation and evaluation more challenging in healthcare.

The complexities arising from the evolutionary, cultural, political and legal influences make an universal definition of this concept quite a challenge. However, a review of common definitions and principles will give a better understanding of the multiple facets that this concept denotes. These have been analysed and presented in table 1.1. The patterns and limitations in the way definitions had been constructed and used previously, is discussed following this table.

Table 1.1. Definitions and principles of patient-centredness from prominent literature

Author and context	**Definitions and principles**
Balint (1969, p.269) in patient-centred medicine	Understanding the patient "as a unique human being".
Laine and Davidoff (1996,) in patient-centred care (PCC)	'Care closely congruent with, and responsive to patients' wants, needs and preferences'.
Institute of medicine (IOM) in the US (2001, p.3) in patient-centred care	'Providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuing that patient values guide all clinical decisions'.
The Agency for Healthcare Research and Quality (AHRQ,2011 ,Ch. 5) in patient-centred care	"Patient-centred healthcare establishes a partnership among practitioners, patients and families to ensure that decisions respect patients' wants, needs and preferences and solicit patients' input on the education and support they need to make decisions and participate in their own care".
The European Picker institute (1987, p 1) in patient-centred care	• respect for patients' values, preferences and expressed needs • coordination and integration of care • information, communication and education • physical comfort • emotional support and alleviation of fear and anxiety • involvement of family and friends • transition and continuity • access to care

Stewart, (2001, p 445) in medical consultations	Patient centred care • "explores the patients' main reason for the visit, concerns, and need for information; • seeks an integrated understanding of the patients' world—that is, their whole person, emotional needs, and life issues; • finds common ground on what the problem is and mutually agrees on management; • enhances prevention and health promotion; • enhances the continuing relationship between the patient and the doctor • `being realistic' about personal limitations and issues such as the availability of time and resources".
Mead and Bower, (2000) in family practice	• The biopsychosocial perspective- a consideration of the social, psychological and medical aspects of illness • The patient as a person- consideration of an individuals' experience of illness • Sharing power and responsibility-in order to ensure informational needs are met, decisions are jointly made and responsibility for health is shared between the patient and provider • Therapeutic alliance-establishing a bond with the patient and building a working relationship to achieve common goals and • The doctor as a person- reflective practice regarding the influence of the clinician's personality and their subjective experiences on patient care.
Leplege *et al*., (2007, p:1556-59) in rehabilitation (with a focus on cognitive and general rehabilitation)	• 'Addressing the person's specific and holistic properties' - addressing the uniqueness of the individual at the same time considering and catering to all different aspects of health such as the emotional and social needs. • 'Addressing the person's difficulties in everyday life'- addressing the difficulties in everyday life and intervening in the environment particular to that

	person. • 'Person as an expert: Participation and empowerment'- Considering the patient to be the expert in their situation and further facilitating their decisional autonomy by active involvement and information sharing. Social participation and participation in the process are a focus of this domain. • Respect the person 'behind' the impairment or the disease'-considering the patients' strengths and viewing them with a positive regard (accepting them as they are).
Lawrence and Kinn, (2012,p. 322) in stroke rehabilitation.	• "Identifies individuals' communication skills and utilizes appropriate and effective communication strategies in all interactions between the health-care professional and the individual • Identifies outcomes that are valued and prioritized by individuals • Identifies outcomes that reflect the desired quality of participation • Monitors and measures outcomes at appropriate times and points in the rehabilitation process • Uses the resultant information to inform the patient, health-care professional's decision-making process."

1.6.1 Analysis of the concept of patient-centredness

The definitions of the concept set out in table 1.1 seem to have evolved over time. Early definitions (Balint, 1969; Laine and Davidoff, 1996) imply that the responsibility of patient-centred care (PCC) rested with the health professional and the system. This could still reflect a paternalistic approach where the patients have no responsibility over their own health. The professional guideline from the Institute of Medicine (IOM) and Committee on the Quality of Health Care in America, (2001) largely reflects this philosophy, but with a shift to considering medico-legal implications (Kennedy, 2001). The socio-cultural changes in the 70s with the disability movement and a more consumerist perspective from patients could have helped cause the shift towards that of an equal partnership.

The focus of PCC has expanded over the last twenty years or so from the individual professional-patient relationship to entire healthcare systems, and thus includes collaboration amongst all the various stakeholders (AHRQ 2001); the patient's role within the healthcare system having evolved from being a recipient to an empowered partner. However, the responsibility of empowerment still lay with the provider.

The concept evolved to encompass the idea of patients becoming more responsible, not just for their own health (Mead and Bower, 2000; Stewart, 2001), but for contributing opinions towards improving the quality of health services (Coulter, 2002). For example, the Health and Social Care Act (2012) stipulates that service users must be involved in determining the clinical commissioning of services. Hence there is a visible shift from the singular focus on intervention for one person's health to a wider focus on patients' experience, in general, with all aspects of healthcare. Thus patient-centredness has become an indicator of quality of care in the healthcare system within its guidelines and standards for practice (DoH, 2005)

The European Picker Institute, a non-profit organisation who support organisations and individuals to improve healthcare, helped to develop the principles of PCC in 1986. They offered an influential framework supporting delivery of high quality patient-centred health and social care internationally (Picker Institute, 1987). The Picker Institute, working in partnership with the DoH and the regulators of NHS England, survey and monitor quality of healthcare and assemble evidence to drive policy and practice. The principles they outline are criteria to implement and measure patient-centredness in practice and provide a bridge between theory and practice.

The definitions and principles of PCC analysed thus far were derived from disciplines other than rehabilitation and could omit principles that are valued in rehabilitation (Gzil *et al.*, 2007). Hence researchers have analysed the concept based on disability studies and mental health and have isolated components relevant to the field of rehabilitation (Ozer and Kroll, 2002; Leplege *et al.*, 2007). In particular, they found that key aspects of rehabilitation such as safety, health promotion and avoidance of risk factors, using best evidence for the best possible outcomes, and roles and responsibilities of patients, were not mentioned as parts of PCC within the generic literature. Nevertheless, despite the wide use of terminology relevant to PCC in rehabilitation literature, principles relevant to rehabilitation, especially for goal-setting are still unclear.

The attempt to define patient-centredness in the context of stroke rehabilitation was carried out by Lawrence and Kinn (2012); they reviewed the stroke-specific literature, scrutinised general qualitative literature that mentioned aspects of patient centredness, and derived themes from this data. This work resulted in a modified definition of the concept which is focused on patient-centred outcome measures. Any definition of patient-centredness, founded

on one component i.e. outcomes, is limited in its application to processes within rehabilitation since these processes are multifaceted. For example, goal-setting involves informing, problem-solving, defining goals, negotiation and review. Hence there is a need for a broader definition of PCC that considers this complexity and encompasses appropriate dimensions (Morgan and Yoder, 2012).

Accordingly, Morgan and Yoder (2012), in a recent attempt to summarise the entirety of the dimensions of PCC, suggested a definition: "PCC is a holistic (bio-psychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care." (p.8).This definition binds together the principles of holistic, personalised care for an empowered patient, while being flexible and maintaining a good relationship. However this definition narrows the scope down to transactions between the healthcare professional and the patient leaving out wider public-health considerations such as access to care, integration of services, contribution to quality monitoring and development of services.

Finally, in keeping with the philosophy of this study, it was critical to consider what is known to date of the patients' understanding of patient-centredness. According to patients who were involved in rehabilitation and participated in Cott's (2004) study , PCC was "an overall philosophy…in which, patients have an active involvement in managing healthcare… in partnership with service providers who understand and respect their needs" (Cott, 2004, p. 1418). Patients viewed empowerment and the therapeutic relationship as vital to patient-centred rehabilitation. Potentially, these two aspects are basic prerequisites for them to raise wider and more personal issues relevant to their health. Though this definition is not

comprehensive, Cott's work highlights the patient's priorities and must be represented in any framework for PCC.

Considering the above attempts to provide a universal definition, it is clear that to bind all principles attributed to PCC within one complex definition might not be plausible. The concept has grown to accommodate the individual, the professional, the care system, their interaction and communication. There is considerable overlap of the meanings and principles amongst the various definitions (table 1.1). However, what the concept invariably seems to assume is a context of holistic care based on a biopsychosocial model. This warrants a comprehensive approach to care, focusing on individualistic needs which are identified through collaborative working. Above all it requires care processes to be founded on values of respect, understanding and empowerment. To summarise, PCC is not a unified but a multidimensional approach, the dimensions of which need to be made explicit in order to be operationalised. Therefore rather than applying a generic definition of PCC, where applied, it should be defined and its dimensions set out clearly for that specific context of practice.

1.6.2 Is patient-centred goal-setting (PCGS) required for stroke rehabilitation?

Considering the previously discussed persuasive drivers for PCC in general, we need to understand what this approach could offer to the process of goal-setting, before determining the need for the study. Rehabilitation by its definition and scope aims to maximise an individual's potential; hence the focus is on the individual. In stroke, where each patient's needs are unique, patient-centred rehabilitation requires an opportunity for patients to voice their needs, to describe their individual situations, to plan for their rehabilitation and share in decision making regarding their goals (Ozer and Kroll, 2002; WHO, 2007; ISWP, 2012). Thus the attributes of the patient-centred approach discussed in the earlier section seem to be

most suitable to fulfil the aims of rehabilitation and its key process of goal-setting for stroke rehabilitation. For example ISWP (2012) guideline 3.12 states that patients should be involved in setting goals for rehabilitation. Whether these guidelines are implemented is being audited at regular intervals by the Sentinel Stroke National audit program which includes a counting exercise of whether patient goals were set within a specified time (ISWP, 2011; RCP, 2015). However, whether goal-setting is patient-centred, as recommended, is not audited.

A review of the psychological theories in rehabilitation suggests that a key aspect of PCC, i.e. patient involvement, would increase the sense of control over their rehabilitation (Jones, Mandy and Partridge, 2000; Bandura and Locke, 2003). Regaining even a partial sense of control is important as the patient is in a new life situation due to the stroke and in the hospital environment which can cause a sense of lost control. Based on the locus of control construct, perceived control has been shown to influence outcomes of disability in stroke (Johnston *et al.*, 1999). Additionally it has been shown that patient involvement can improve self-efficacy beliefs (belief about one's ability regarding a particular behaviour), which can lead to better motivation, better effort, commitment to goals and potentially improved outcomes (Dixon, Thornton and Young, 2007; Phipps and Richardson, 2007). Moreover, stroke is a long term condition in which restoration of one's potential should involve empowerment and sharing of responsibility for health, supporting one's ability to adhere to treatment or to self-manage in the long-term (Michie, Miles and Weinman, 2003). The sense of control through PCGS could facilitate long-term self-management and coping. Thus PCGS could potentially have positive psychological influences resulting in better outcomes specific to the individual.

Additionally, most directives governing professional practice within stroke rehabilitation include principles of patient-centredness for goal-setting. According to the British Society of Rehabilitation Medicine, 'Patient/clients and/or their families should be involved in the goal-setting process where possible, and should be kept informed of the aims of the programme. The individual should be involved as actively as possible in goal setting. The goals should be agreed between the individual, their family, carers, and the rehabilitation team' (Turner-Stokes *et al.*, 2000, p.479). These principles have been reiterated in the latest national clinical guidelines for stroke (ISWP 2012, Guideline 3.12.1) which states that:

> Every patient involved in the rehabilitation process should:
>
> a) have their feelings, wishes and expectations established and acknowledged,
>
> b) participate in the process of setting goals unless they choose not to or are unable to participate because of the severity of their cognitive or linguistic impairments,
>
> c) be given help to understand the nature and process of goal setting, and be given help to define and articulate their personal goals.

A consideration of the above guidance reveals that, in addition to involving the patient in the process and negotiating goals, the scope of goal-setting expands to include sharing of information and also to acknowledge patients' contribution. The inclusion of family in the process is yet another aspect that has been reiterated; however, there are confounded views on whether families actually target the best interests of the patients (Glazier *et al.*, 2004). Hence it was decided that for this study patient collaboration will be the main focus.

1.7 Need for research in this area

Due to the fact that stroke results in a huge burden for the patient, provider and NHS, there is a need to identify optimal methods of care to reduce these burdens. The above consideration, that PCGS could help improve sense of control, self-efficacy and motivation sounds promising. Moreover the increasing pressure on health professionals to follow patient-centred practices with a potential for better rehabilitation outcomes make this a pertinent research area.

Since healthcare delivery is required to be based on evidence (Sackett *et al.*, 1996), this much advocated concept of patient-centred care needs to be examined for its scientific credibility. Currently research does not look at entire systems and processes (International Alliance of Patients' Organisations and (IAPO), 2007) and is limited to micro level research i.e. investigating some isolated aspects of patient-centredness such as participation in goal-setting or giving information. So macro level research looking at the entire process of goal-setting, and a comprehensive investigation of different aspects of patient-centredness, is required.

Additionally if PCGS is highly recommended for practice, it is important to know whether it is actually being applied in practice and if so, what the benefits due to its application are. This leads to a further question whether there are currently any holistic methods of goal-setting that are patient-centred. Alternatively if such methods don't exist or they are ineffective, then research needs to build new resources or frameworks by which PCGS can be effectively implemented. Thus research needs to explore and describe the evidence base and practice regarding application and effects of PCGS.

1.8 Research question and research objectives.

The overarching research question for this research is:

What is the influence of patient-centred goal-setting in current stroke rehabilitation practice on outcomes relevant to the patient and the practitioner?

This was broken up into smaller sub-questions

Sub-questions 1,2 and 3: Is goal-setting in stroke rehabilitation patient-centred? How is it implemented? What are the potential benefits of such a process for the patient and the practitioner?

The initial aim of the study was to explore whether goal-setting practices in stroke rehabilitation are patient-centred, what methods were used and with what outcomes, in the literature and in current local practice.

The objectives were stated as

1. To systematically search and evaluate the evidence on the extent, nature and effects of patient-centred goal-setting in stroke rehabilitation using a systematic literature review.

2. To explore local practice regarding the extent, nature and effects of the implementation of patient-centred goal-setting in stroke rehabilitation using qualitative methods.

1.9 Summary of chapter

The increasing burden of stroke on patients' health, due to long term disability, warrants optimal care processes including effective rehabilitation. Rehabilitation should cater to the multifaceted problems (physical, psychological, social and contextual) that are unique to each stroke survivor. Goal-setting during stroke rehabilitation is a key step when these multifaceted, yet individualistic problems can be identified and plans can be made to meet these needs. Since a patient-centred approach aims to tailor rehabilitation to suit individuals, it might be an appropriate theoretical fit for the goal-setting process. However, further research into stroke goal-setting especially that built on principles of patient-centredness is required. This is the broad remit of the current study. The specific objectives stated above have been studied using appropriate methodologies. A systematic review that was carried out to examine the specific literature relevant to understanding PCGS in stroke will be reported in chapter two and the exploration of local practice will be described in chapters three and four.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

A systematic review, to identify literature, appraise quality of literature, and to thematically synthesise findings relevant to this study, is presented in this chapter. This review updates that undertaken in 2010 and subsequently published (Rosewilliam, Roskell and Pandyan, 2011). The reasons for the update were:

1. In response to the substantial problems with standards of care in the NHS (DoH, 2010; Francis, 2013), research related to 'patient-centredness' was evolving fast; delaying updates in an area where there is a fast pace of development could render the previous review meaningless (Moher and Tsertsvadze, 2006).
2. Improvements have been made to overcome certain limitations of the methods previously used, which have been described in relevant sections below.

2.1 Aims of the current review

Since the overall aim of the literature review was to explore the landscape of PCGS in stroke rehabilitation, the scope of the review was kept broad. The aims for this review, as in 2010, were summarised in the two questions given below.

1. How is patient-centredness perceived and employed, by professionals and patients, in goal-setting for patients with stroke for their rehabilitation and to what extent does it happen?
2. What are the effects of applying patient-centredness in goal-setting on the outcomes achieved for patients and professionals?

2.2 Need to define concepts involved

The concept central to this review, 'patient-centredness in goal-setting', involved two key terms *patient-centred* and *goal-setting* that have been variably defined and interpreted in research and practice (Levack *et al.*, 2006a; Leplege *et al.*, 2007). Authors had often used these terms loosely, without any actual engagement of what the concept might mean. Not defining the concepts adequately in the previous review had reduced clarity of the inclusion criteria and hence difficulty in decision making for the researcher during the screening of articles for inclusion (Furlan *et al.*, 2009). Furthermore, this lack of clear outline of the concept and inclusion criteria seems to have made it difficult for some readers to understand the orientation of the previous review (Sugavanam *et al.*, 2012). Hence these key terms 'goal-setting' and 'patient-centredness' were defined at the outset (refer to section 1.3 and section 1.6) to reduce ambiguity in the selection of articles to be included in this review (Higgins and Green, updated March 2011)

2.2.1 Patient-centred goal-setting (PCGS)

Following the analysis of the key concepts within PCGS using the core literature in Chapter one, the following working definition has been set out. 'Patient-centred goal-setting', for the purpose of this review is clarified to include one or more of the following aspects:

a) The facilitation of the active participation of patients by helping them to understand the goal-setting process.
b) Patients should be involved in process of setting goals, planning care and their goals established or their motives explored by members of the rehabilitation team.

2.3 Review Methodology

To reduce redundancy of research effort and wastage of resources, research synthesis of prior work in this area is essential (Wright *et al.*, 2007). Since a systematic review 'systematically assembles' evidence (Cook, Mulrow and Haynes, 1997) and is explicit about the methods (Khan *et al.*, 2003) this method was adopted. The following sections will describe and justify the various methodological steps implemented to conduct the searches, screen, appraise quality, extract data, analyse and synthesise findings. The guidance provided by the Centre for Reviews and Dissemination (CRD, 2009) was followed in addition to guidance from Cochrane database (Higgins and Green, updated March 2011) and other relevant literature throughout the conduct of the review.

2.3.1 Search Strategy

A preliminary search strategy using key words 'Stroke', 'Patient-centredness' and 'Goal-setting' was carried out to identify literature from which related key words were listed. These key words were also 'exploded' using facilities available on the Medline database to identify further terms. Additionally, the involvement of an expert in communications in advisory capacity (CRD, 2009) and the librarian (Booth, 2006) led to use of additional terms synonymous to the key terms and ensured comprehensiveness of the search strategy which was lacking in the previous review (Smith *et al.*, 2011). Though the extensive use of key words might compromise the specificity of the search results (Higgins and Green, updated March 2011), it was decided to have an extensive search strategy in view of the broad scope of the review.

Systematic reviews, traditionally, review quantitative clinical trials and statistically integrate the findings from homogenous studies (meta-analysis) to study effectiveness of interventions and build evidence for practice (Wright *et al.*, 2007). However, the focus of this review on 'the nature and extent of practice' meant that perceptions, views, and experiences of individuals involved in the process and context of practice needed to be examined. Hence studies using qualitative methods were included in this review (Dixon-Woods *et al.*, 2004). Since the review also aimed to explore if there were any effects of the process of PCGS, studies using quantitative methods (Levack *et al.*, 2006a) that measured outcomes of goal-setting were also included in this review.

Use of conventional methods of identifying search terms which involved specifying study designs such as PICOS (Population, Intervention, Comparison, Outcome and Study design) or SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) were avoided

for the following reasons: a) PICOS is focused towards identifying just quantitative interventional studies, b) SPIDER is designed to include all types of studies; however, the indexing for qualitative articles would not necessarily retrieve all relevant qualitative studies despite use of SPIDER (Cooke, Smith and Booth, 2012) and c) the reliability and validity of SPIDER is questionable (National Collaborating Centre for Methods and Tools (NCCMT), 2013).

The search strategy was structured to optimise the retrieval of relevant articles by using Boolean operators 'AND' and 'OR' (Higgins and Green, updated March 2011) and is presented in table 2.1. The use of asterisks or hash-tags for truncated terms was crosschecked on each database to ensure that the appropriate symbol for the particular database was being used following the guidance from library advisor.

Table 2.1. Search strategy showing list of key words, Boolean operators and truncation of key words

Search number	Key Terms	Search number	Key Terms	Search number	Key Terms
1. 2. 3. 4. 5. 6. 7. 8. 9. 10. 11.	"Client centered" "Client centeredness" Client-centered Client-centeredness "Client centrality" Client-centrality "Client centred" "Client centredness" Client-centred Client-centredness Client cent*	41. 42. 43. 44. 45. 46. 47.	Stroke "Cerebrovascular accident" "Cerebrovascular disease" "Cerebrovascular disorder" "Cerebrovascular attack" CVA All the above combined with OR	48. 49. 50. 51. 52. 53.	Goals Goal-setting "Goal setting" Goal-planning "Goal planning" All the above combined with OR
12. 13. 14. 15. 16. 17. 18. 19. 20. 21. 22.	"Patient centered" "Patient centeredness" Patient-centered Patient-centeredness "Patient centrality" Patient-centrality "Patient centred" "Patient centredness" Patient-centred Patient-centredness Patient cent*				

23. 24. 25. 26.	"Patient focused" Patient-focused "Patient focussed" Patient-focussed				
27. 28.	"Patient oriented" Patient-oriented				
29. 30. 31. 32. 33.	"Person centered" "Person centeredness" Person-centered Person-centeredness "Person centrality"				
34. 35. 36. 37. 38. 39.	Person-centrality "Person centred" "Person centredness" Person-centred Person-centredness Person cent*				
40.	All the above combined with OR				
54.	Search 40, 47 and 53 were combined with AND				

2.3.2 The search process

Different approaches were employed to maximise the collection of relevant literature as all relevant publications might not have been uploaded in databases (Bastian, Glasziou and Chalmers, 2010). The first approach used was the electronic search on databases relevant to the topic. They included the AMED, CINAHL (Plus) and SportDiscus from EBSCO which focused on complementary medicine, nursing or sports and rehabilitation studies (CRD, 2009). Due to the multidisciplinary nature of the research question, databases with a broader focus encompassing different health disciplines such as Medline and Psychinfo from Ovid, Science Citation Index Expanded from Thomson and Reuter, and Cochrane from WILEYS were also searched. ProQuest was selected since it provides a cluster of databases relevant to various science disciplines which can be searched simultaneously.

Multiple databases (listed in appendix 2.1) were chosen to ensure thoroughness despite repetition of effort and overlap in results of searches. The above databases were also chosen due to their potential for saving search strategies and history for future reference, the ability to collect articles in personal online folders and the ability to transfer these citations directly to a bibliographic database. Following the selection of the databases, the search strategy (table 2.1) was inputted in each of them and searches were run for the period between January 1980 and December 2014. This time period was chosen as the concept of patient-centredness started gaining currency in the late 80s and early 90s in particular, following on from the disability movement and rise of a more consumerist relationship between doctors and patients (Leplege *et al.*, 2007). Limiters were used to specify aspects such as ‘search in abstracts’, studies that involved humans, and ‘published in English language’ to focus the searches.

The second approach involved the manual scanning of reference lists from the reviews and the primary articles that were shortlisted following the above approach (CRD, 2009). Thirdly the search engine 'Google Scholar' was used to look for publications related to theses identified through database search, since it was unrealistic to evaluate entire theses for this review (Ogilvie *et al.*, 2005). Additionally, publications related to conference abstracts and registered protocols for trials or reviews were also searched for, using the authors' names and key words. The first two pages returned from the search (20 search results) were screened for relevance. It was not possible to access grey literature by contacting the authors or manually searching journals to identify additional literature.

2.4 Screening and selection process

The researcher screened the citations and abstracts on the various databases and rejected those clearly outside of the subject area (CRD 2009). Those in the subject area were then exported along with their abstracts into the bibliographic software Endnote, version X7 2.1.

At the next stage the abstracts collected from the electronic search along with those shortlisted from the secondary searches were screened against the inclusion/exclusion criteria set out by the researcher (table 2.2). A second reviewer with a master's degree in physiotherapy was briefed on the research topic, questions, focus of review and the criteria prior to the screening. Both reviewers independently screened and recorded decisions regarding acceptance or rejection of these abstracts. In some cases both reviewers found it hard to decide on inclusion due to the limited information contained in the abstracts. It was decided to take these abstracts to the next stage of screening of full text articles (CRD 2009). The decisions made regarding

the numbers of abstracts to be included or rejected at this stage is listed with reasons in appendix 2.2.

2.4.1 Selection criteria

The selection criteria were developed to be 'purposive' (e.g. articles only from rehabilitation of stroke) in order to increase the specificity of included articles (Booth, 2006). The criteria used for screening of articles for inclusion and exclusion are presented in table 2.2 along with pragmatic reasoning and scientific justification.

Table 2.2. Inclusion and exclusion criteria for screening of abstracts and articles

Inclusion criteria	**Justification**
Studies that recruited adult patients with stroke.	Patients with stroke have multifaceted long-term disabling consequences and need rehabilitation based on PCGS (ISWP, 2012)
Only stroke patients' data from studies that involved patients with other conditions will be included.	There is huge variability in the way patients cope, how they are managed, prognosis and outcomes for patients with different chronic illnesses (Andreassen and Wyller, 2005).
Studies that involved healthcare professionals who worked with patients with stroke.	It is a professional requirement to be patient-centred in setting goals for patients with stroke (ISWP, 2012).
Studies that investigated the process of 'goal-setting'[1] for rehabilitation of patients with stroke.	Goal-setting is a key step in planning for healthcare which is individualistic to a person and hence it needs to be built on patient-centred principles (WHO, 2006; ISWP, 2012).
Studies that looked at activities that were defined as meaningful to the patient or client-chosen activities.	Meaningful activities and client-chosen activities are terms used within rehabilitation literature to reflect patient chosen functional goals (Randall and McEwen, 2000)
Studies that have investigated the concept of PCGS either to understand views, perceptions, experiences and application of the principles or evaluate the influence of applying principles of PCC[2].	

[1] This concept is defined in section 1.3 of chapter 1.
[2] This concept is defined in section 1.6 of chapter 1.

Peer reviewed publications	
Articles published between January 1980 and December 2014.	This range was specified as literature revealed that the concept of patient-centredness evolved from other social movements and was initially adopted in the field of rehabilitation in the late 70's and early 80's (Leplege *et al.*, 2007)
Limited to English language	Non-availability of translation facilities for articles in other language (Smith *et al.*, 2011). Though language bias is prevalent with English articles, there is limited impact on findings (Wright *et al.*, 2007). Further, based on background reading, patient-centredness was a concept relatively unused in the eastern literature and hence much literature in languages other than English was not expected (Furlan *et al.*, 2009).
Exclusion criteria	**Justification**
Studies that included paediatric population with stroke.	Rehabilitation goals are influenced largely by parents and carers in children who have suffered a stroke. Goal-setting tends to be more family centred rather than just focus on patient (Galvin *et al.*, 2010).
Research that studied families and carers of patients with stroke.	Inclusion of family oriented studies will cause deviation of focus to family-centred care. Moreover research has shown that families sometimes have their own agenda in setting goals for patient which may not actually be patient-centred goals (Glazier *et al.*, 2004; Brown *et al.*, 2014).
Goal-setting outside the context of rehabilitation such as drug delivery	The focus of study is rehabilitation rather than medical management of patients

plans.	with stroke.
Studies that have not described how the GS process involved the patient.	
Interventional studies that did not relate intervention to PCGS or measure outcomes relevant to patient-centred goal-setting.	
Articles that suggest that tools or outcomes were patient-centred (such as GAS and COPM) without adequate information on application of patient-centred principles or justification for why they considered these measures patient-centred.	
Theses relevant to the topic.	Limited scope to read and evaluate entire theses in this area.
Editorials, conference abstracts and poster presentations.	The limited information available from these sources will not be adequate to judge the quality of work and also get adequate information from the work (Wright *et al.*, 2007)
Conceptual frameworks	Papers that had proposed models or frameworks for PCGS but had not implemented or evaluated them were considered to be similar to reviews or expert opinions (as guidance) and not as primary research.

2.4.2 Screening of articles

Full text articles relevant to the shortlisted abstracts were collected and read by the researcher to assess for relevance based on the inclusion and exclusion criteria. The researcher had discussions with the second reviewer and the supervisory team when there was lack of clarity regarding inclusion of certain articles (Furlan *et al.*, 2009). Since the second reviewer did not read all the shortlisted articles due to time restrictions, a calculation of kappa statistic that would have improved the reliability regarding inclusion of articles (CRD, 2009) was not possible. Due to the inclusion of qualitative literature and the complexity of concepts, it was recognised that a certain level of academic judgement while making decisions regarding inclusion of articles would be required. Therefore a strategy of consensus based on critical discussions was adopted for this review. The list of articles rejected after reading full text articles along with reasons is provided in appendix 2.3. The final list of articles included in the review is presented in appendix 2.4 and appendix 2.5, the tables used for data extraction.

2.5 Data extraction

The data extraction forms used for the previously published review were considered adequate to extract data from the selected articles and hence were not piloted for this review. Depending on whether the study was qualitative or quantitative, two types of data extraction forms were used. The quantitative data extraction table (appendix 2.4) and the data extraction table for the qualitative studies (appendix 2.5) were developed based on literature (Harden *et al.*, 2006; CRD, 2009). The data from the mixed methods studies was inputted in relevant sections of both the qualitative and quantitative data extraction tables. These data extraction

tables not only helped to summarise the studies but also displayed the data for further analysis and synthesis (Cooper *et al.*, 2001).

2.6 Quality appraisal

Numerous tools for appraising quality of articles were available; yet no single tool has been recommended for appraising studies that had used various designs and methods within the quantitative and qualitative approaches (CRD 2009). Secondly, most tools assign a score for different items that contribute to methodological rigour and these summated scores of quality do not elaborate on specific methodological strengths and weaknesses. Moreover, studies have shown that different scales give weight to different items; hence a summary score using one or more tools is non-reliable (Jüni *et al.*, 1999). Therefore it was decided that the methodological concerns would be critically evaluated using relevant checklists, issues summarised (appendices 2.6 and 2.7) and these issues will be discussed within results section rather than providing quality summary scores.

The following tools were considered for the quality appraisal of articles for this review:

- The Cochrane risk of bias tool for clinical trials though useful to judge internal validity did not assess generalisability, reporting and ethics. Moreover it was not useful to appraise studies of different designs included in this review (Higgins and Green, updated March 2011, Chapter 8)
- The CONSORT checklist for randomised clinical trials and the critical appraisal skills program (CASP), though comprehensive for analysis of quality aspects other than bias

(Moher *et al.*, 2010), were not appropriate due to the variability of designs of the studies within this review.

- Though developed for the assessment of public health literature, the "Quality Assessment Tool for Quantitative Studies" was chosen due to its scope to appraise selection bias, design, data collection methods, recruitment and retention, intervention integrity and analysis (Higgins and Green, updated March 2011).

- Qualitative studies were appraised using a criterion checklist developed by the Economic and Social Research Council (ESRC) (Thomas *et al.*, 2003) which had been derived from multiple sets of pre-existing quality appraisal criteria. It covered quality of reporting of study's aims, context, rationale, methods and findings, reliability and validity of data collection, analysis and findings. These items were used as broad reminders to critically examine these areas.

- The COREQ qualitative tool (Tong, Sainsbury and Craig, 2007) was used for appraising trustworthiness in greater depth within areas identified by the ESRC tool.

The other challenge that was identified at this stage was whether articles should be excluded based on their methodological robustness. If articles with weak methodologies were included, the systematic review's findings would ultimately be considered to lack robustness, thus limiting wider adoption of the findings in policy and practice (CRD 2009). However, there was no empirical evidence regarding exclusion of qualitative articles based on quality (Thomas and Harden, 2008). Moreover, considering the broad scope of the review, which aimed to understand the landscape of this topic and the limited number of articles retrieved,

the researcher decided to present the findings from all the included articles regardless of their methodological rigour (Thomas and Harden, 2008).

2.7 Data analysis and synthesis

Confronted with literature with diverse methodologies, the researcher considered various methods (Dixon-Woods *et al.*, 2004; CRD 2009) to provide a coherent synthesis of findings, while still upholding the systematic, reproducible, rational and explicit principles of conventional reviews. Some methods that were considered are discussed below.

Critical interpretative synthesis, though it results in a theoretical framework of concepts using critical and reflexive process (Dixon-Woods *et al.*, 2006), was rejected, since the aim of this review was to aggregate the evidence to inform future empirical work rather than to build major theory. The method of thematic synthesis allows sufficient flexibility to integrate findings under prominent themes identified in studies either descriptively or using interpretation. However, the literature still lacks clear directions regarding whether themes must be weighted for frequency or explanatory value, or whether they should be theory driven or data driven (Dixon-Woods *et al.*, 2004) and hence this method was rejected.

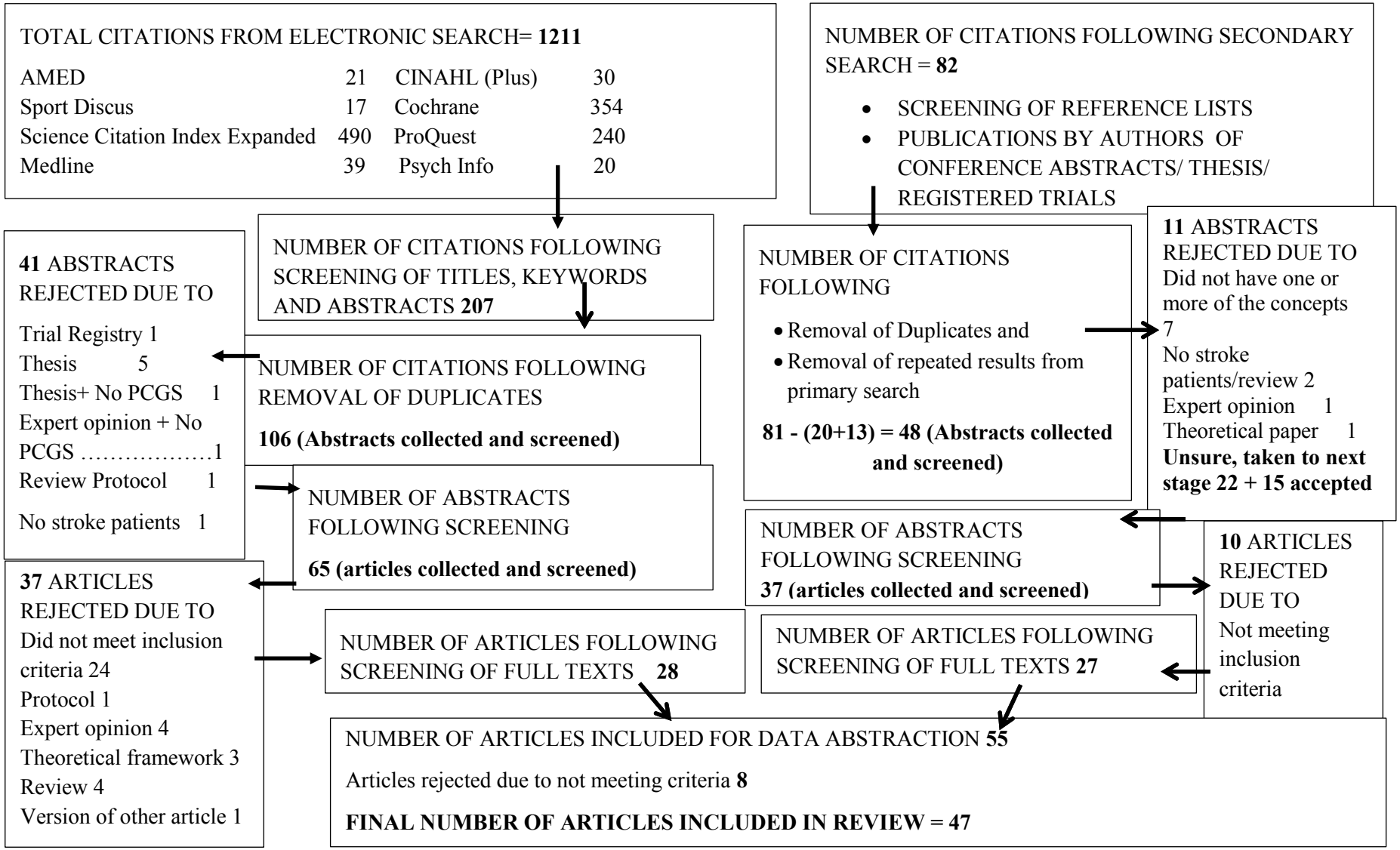
Meta-ethnography is a method where concepts are identified from papers, compared and contrasted and synthesised using higher order constructs or line of argument synthesis (CRD 2009). New interpretations are derived based on this synthesis. Limitations in integrating quantitative literature within meta-ethnography and procedures that require multiple researchers' input caused rejection of this method for this review.

Qualitative synthesis had to be interpretative (yet not distanced from context), structured and auditable; most importantly the synthesised material should be amenable for integration with the findings from the quantitative studies (Thomas *et al.*, 2004). Hence, the researcher decided to adopt the qualitative meta-synthesis method where the findings from the qualitative articles were pooled, concepts were identified, analysed, grouped under categories and synthesised using themes and subthemes. The analysis of findings from qualitative studies involving allocation of codes and categories before final themes were derived is illustrated in appendix 2.8. Meta-analysis of quantitative results was not possible due to the heterogeneity of subjects, intervention and outcomes in the included studies. Therefore the findings from the quantitative studies were summarised using narrative synthesis (Wright *et al.*, 2007), matched and integrated with the themes from the qualitative synthesis (CRD 2009).

2.8 Results

The numbers of articles retrieved, screened and shortlisted at every stage has been documented in the flow diagram below (figure 2.1). The general characteristics of the studies and the participants involved in these studies have been summarised in sections 2.8.1 and 2.8.2. The individual studies have not been identified in these summaries, but can be identified from appendices 2.4 and 2.5.

Figure 2.1. Results of the searching, screening and shortlisting of articles for the review- PRISMA diagram. (Moher *et al.*, 2009)



2.8.1 Characteristics of the studies

The final number of articles included in the review was 47 of which 17 were quantitative, 25 were qualitative and 5 were mixed methods. Most studies were conducted in the western population and a few in Australia and New Zealand. Fourteen of the studies, the highest number, were done in the UK. There were none from Asian, South American, African and Middle East countries (except for one study from Israel). This fact raises the question whether the concept of patient-centredness is peculiar to western culture.

The study settings varied from acute to inpatient rehabilitation to a community-based setting such as in patients' homes. Most studies had been conducted in inpatient rehabilitation facilities (23) with only five of these described as being in acute care. This potentially is due to difficulties implementing the process of collaborative goals-setting with patients in acute rehabilitation and also challenges in researching complex processes in acute care. There were moderate numbers of studies conducted in the community (12), closer to the patients' own environment, which seemed to be a suitable context for PCGS. Most studies looked at patients' perspectives (12) or were interventional studies with patients (13). There were only seven studies that involved both patients and professionals; hence most studies gave a one sided view of the process.

2.8.2 Characteristics of participants

The numbers of participants varied from one to 188 in the studies, the mean age of the patient participants was between 33-92 years, and their stroke severity ranged from mild to moderately severe. Most studies included patients with cognitive and understandable communication abilities except in two studies (Boonstra, Wijbrandi and Spikman, 2005; Rohde *et al.*, 2012) due to the demands of collaboration in the goal-setting process and

participation in the research study. There were eight studies with multiple professionals' involvement reflecting the multidisciplinary working within the goal-setting process. Therapists, especially physiotherapists and occupational therapists, were involved in most studies (18). Nurses were the least involved professional group, (4) suggesting that in the rehabilitation environment, therapists played the key role in goal-setting.

2.8.3 Results of the meta-synthesis of the findings

The themes derived from the qualitative analysis of the findings integrated with the quantitative findings from the studies have been presented in this section. The methodological critique of the studies has been integrated with these findings.

2.8.3.1 Principles of PCGS

Primarily, a person's motives, expectations and their abilities for goal-setting were individualistic (Alaszewski, Alaszewski and Potter, 2004; Rohde *et al.*, 2012). Patients' motives were to avoid frustration and embarrassment and earn pride, independence and happiness. They contextualised their goals within their personal biographies and aimed for the levels of activity they had before stroke, to achieve their former social identity or to gain a new identity (Bendz, 2003; Alaszewski, Alaszewski and Potter, 2004; Rohde *et al.*, 2012; Brown *et al.*, 2014). Consequently, their goals were around transferable skills, return to work, (Timmermans *et al.*, 2009), functional recovery, self-care and leisure (Alaszewski, Alaszewski and Potter, 2004; Boonstra, Wijbrandi and Spikman, 2005; Laver *et al.*, 2010). Thus unique and complex motives led to complex, ambitious and long-termed goals in some patients (Brown *et al.*, 2014).

However, some patients adopted a day by day approach to the future (Brown *et al.*, 2014) by setting short-term goals, probably because degree of recovery is not predictable. Nevertheless, these short-term, low level goals were ultimately linked to their motives for participation (Timmermans *et al.*, 2009). For example patients who wanted to improve their communication skills wanted to achieve socialisation targets such as hobbies (Rohde *et al.*, 2012). Though above findings are derived from just two studies, one with a small qualitative component (Timmermans *et al.*, 2009) and the other focused on a subgroup of patients with aphasia (Rohde *et al.*, 2012), there is an indication that short-term goals should be linked to long-term goals to cater to the unique motives of a patient (Huby *et al.*, 2004; Levack *et al.*, 2011).

Often patients wanted a better understanding of the process of goal-setting (Holliday, Ballinger and Playford, 2007). They suggested that for PCGS to result in explicit, comprehensible and tailored goals that were meaningful to them (Young, Manmathan and Ward, 2008), they ought to get involved in defining needs, goals, priorities and outcomes (Cott, 2004). Though these opinions represented collective knowledge from focus groups, how well they reflected the mainstream view of stroke survivors is uncertain, since only one of the six focus groups in Cott's study involved stroke survivors.

The above principle of collaboration was also suggested by professionals in many studies (Northen *et al.*, 1995; Wressle, Oberg and Henriksson, 1999; Boutin-Lester and Gibson, 2002; Young, Manmathan and Ward, 2008; Hersh *et al.*, 2012a). Professionals suggested that collaboration should lead to shared understanding and agreement on goals (Wottrich *et al.*, 2004). Only then can goals address patient perceived problems and needs (Hale and Piggot, 2005), motivate (Hersh *et al.*, 2012a), and be meaningful to patients and relevant to their

environment (Daniels, Winding and Borell, 2002; Hersh *et al.*, 2012a). However, the above collaboration principle could only follow if patients chose and were able to participate (Lloyd, Roberts and Freeman, 2014).

Rather than collaboratively setting goals, certain professionals prioritised working towards a relationship with patients or bonding (Lawler *et al.*, 1999; Playford *et al.*, 2000). They felt that it was their responsibility to safeguard patient morale against unsafe and unrealistic goals while retaining hope (Lloyd, Roberts and Freeman, 2014); therefore they tended to restrain autonomy of patients in deciding goals (despite finding this an uncomfortable position to be in) (Daniels, Winding and Borell, 2002). Above all, they preferred not to demotivate patients or lower patients' level of commitment by inadvertently influencing the goal-setting process (Lawler *et al.*, 1999). Despite evidence of credibility presented by Lawler et al., (1999) through multiple quotes from different sources for triangulation, transferability of these opinions is questionable since this study was conducted with a small subgroup of specialist nurses.

2.8.3.2 Extent of patient participation in goal-setting

Patient perception of participation, a key aspect of PCGS, was measured in some studies quantitatively using structured questionnaires. In a survey carried out with 30 patients and 11 OTs, to assess their perceptions of participation in a client-centred process, 72% of OTs said they encouraged their clients to participate to set their goals (Maitra and Erway, 2006). Interestingly, only a fraction of clients said they had assisted in setting goals though 76% of them remembered more than half of their OT goals. This implies that perhaps goals were conveyed to them. In line with these findings, Almborg and colleagues who studied patient participation in goal-setting using Patients' Questionnaire on Discharge Planning (P-QPD),

found that only 29% percent of the 188 participants perceived they had participated in a discussion of goals for treatment (Almborg *et al.*, 2008). Patients who had a stay longer than 30 days and who were dependent, had higher mean scores of their perceived participation, implying longer hospital stay was conducive to participation in goal-setting. Nevertheless, these surveys were built for purposes other than to explore PCGS and hence responses could have been biased by the wider aims of the survey.

2.8.3.3 Challenges to PCGS

Various challenges were identified by professionals and patients in involving patients routinely in goal-setting (Wressle, Oberg and Henriksson, 1999). Patients and professionals suggested that patient involvement in goal-setting was limited due to the unpredictability of the time and extent of recovery from stroke (Laver *et al.*, 2010; Brown *et al.*, 2014), mood disturbances (anxiety, depression and coping) (Playford *et al.*, 2000; Leach *et al.*, 2010; Lloyd, Roberts and Freeman, 2014) and fatigue (Brown *et al.*, 2014). Patients suggested feeling unprepared to make decisions especially during acute stages (yet had set goals in the acute phase) (Laver *et al.*, 2010). This inconsistency was perhaps due to recollection bias, since patients were questioned a few months after stroke regarding their ability to set goals early after stroke. Nonetheless, professionals have suggested that patients' lack of readiness to set goals could be due to the following reasons: illness severity and not knowing enough about their condition, their disabilities, comorbidities and rehabilitation (Daniels, Winding and Borell, 2002; Suddick and De Souza, 2006).

According to professionals, getting to know the patient and understanding cultural differences took time which was limited in the care settings (Playford *et al.*, 2000; Leach *et al.*, 2010; Lloyd, Roberts and Freeman, 2014). Further patients' communication, cognitive problems and

the institutional context, (Suddick and De Souza, 2006; Levack *et al.*, 2009; Rohde *et al.*, 2012) which did not help patients to make connections to their home environment, resulted in less meaningful goals to be set (Daniels, Winding and Borell, 2002; Rohde *et al.*, 2012). These challenges to establish a therapeutic rapport were derived from studies involving different professional groups using different methods for data collection. Therefore, this is a reliable indication that MDTs require further reflection and training on the use of their time and communication in the goal-setting process. In addition to the above challenges, professionals had to manage multiple expectations of the team, organisation and external agencies along with patient and family (Lloyd, Roberts and Freeman, 2014). Therefore, they produced goals that were deemed acceptable in such demanding situations.

Professionals were missing key aspects of PCGS such as eliciting concerns, rating goals or explaining participation in goal-setting (Northen *et al.*, 1995). Ten years on, over half of the professionals in a UK wide survey stated that they gave information about goal-setting during patients' hospital stay; however, goals were set by practitioners during therapy sessions (Holliday, Antoun and Playford, 2005).This study implied that practitioners involved patients partially by sharing information. Contrarily, another study involving professionals from different centres in the UK did not identify any form of patient involvement in the process (Suddick and De Souza, 2006). The above survey studies do not explain reasons for such constrained practice; however, a methodologically rigorous observational study (Parry, 2004) found that only eight out of 74 observed therapy sessions involved goal-discussions. Routinely problems and solutions were suggested by therapists and in rare situations where patient involvement was sought the concerned therapist had to derive problems using repeated constraining questions. Nevertheless, in most situations, professionals believed that patients

delegated the responsibility of goal-setting to professionals due to their low confidence (Playford *et al.*, 2000; Lloyd, Roberts and Freeman, 2014).

2.8.3.4 Strategies for PCGS

Patients considered their own self-determination, encouragement of others, support of family members (Brown *et al.*, 2014) and information provided by the professionals (Holliday, Ballinger and Playford, 2007) as factors that enabled their involvement. They suggested participation in team meetings, documenting and sharing a copy of goals and updating progress in goals to facilitate their involvement (Young, Manmathan and Ward, 2008). Additionally, therapists suggested introducing their roles, educating patients about the rehabilitation process (Levack *et al.*, 2011) and using information pamphlets (Elsworth *et al.*, 1999) to improve the process. Therapists also suggested explaining goals using simple language, involving patients' families in setting goals, and documenting patient goals in notes (Northen *et al.*, 1995) to facilitate PCGS. However, the majority of the above-mentioned strategies were not tested for their efficacy empirically.

The patients and therapists in the STRENGTH program (Gustafsson *et al.*, 2014), wherein therapists took inpatients home for one day a week for assessment in their own home environment (Playford *et al.*, 2000), suggested that relevant, realistic and individualistic goals had been formulated. Moreover, domiciliary goal-setting and evaluation of goal achievement was found to enable achievement of patients' main goals (Boonstra, Wijbrandi and Spikman, 2005) suggesting that the home environment is more conducive for collaborative goal-setting.

In certain neuro-rehabilitation units, professionals suggested setting goals based on priority areas identified by patients (Playford *et al.*, 2000) or using structured interviews and

questionnaires to identify higher level patient goals (Elsworth *et al.*, 1999). However, an audit of their goal-setting records by Elsworth and colleagues revealed that the above questionnaire had been administered in 51% of cases, handicap-based aims were recorded in 66%, and aims for reducing emotional problems were recorded in 28% of cases only. Thus these structures had not been optimally used, potentially due to limitations in staff motivation, knowledge of theory and philosophy of PCGS (Elsworth *et al.*, 1999) and training for communication (listening, lateral thinking and ability to provide guidance) (Hale and Piggot, 2005).

Therapists, at times acted as patient advocates - a mediator between the team and the patient in the negotiation of goals (Lloyd, Roberts and Freeman, 2014). In a structured keyworker role, nominated professionals advocated for patients during goal-setting (Holliday, Ballinger and Playford, 2007; Young, Manmathan and Ward, 2008). However, frequent interaction and good rapport between the patient and their keyworker was still essential to make this advocacy role effective.

Structured tools such as COPM, GAS or Life Goals Questionnaire to elicit and negotiate goals, were suggested to improve patient involvement (Playford *et al.*, 2000; Leach *et al.*, 2010). In addition to improving patients' perception of active involvement, COPM was also shown to improve patients' ability to recall their goals (Wressle *et al.*, 2002). A goal-menu was recommended to incorporate patient, family and teams' perspectives (Glazier *et al.*, 2004) on functional, medical, psychosocial aspects and future planning. Thus tools used for assessing outcomes could help improve PCGS, but should be adequately flexible to identify goals not on the menu.

When a combination of strategies including patient involvement in team meetings, involvement of doctors and the use of modified forms for goal-setting, was employed in a

quasi-experimental study, significantly more patient needs were considered (p=0.007), and more patients were involved (p<0.001) compared to the routine process (Monaghan *et al.*, 2005). Despite the possibility of interventions being influenced by who was leading the team meetings, how informed the staff were about documentation and how informed the carers were about participation, this study highlighted the need for complex interventions to improve PCGS.

2.8.3.5 Impact of PCGS and the lack of it

Therapists suggested that patients would be more motivated, their time would be used effectively and holistic management would be possible if PCGS was done (Leach *et al.*, 2010). They also reported that goals negotiated with patients were more successful (Playford *et al.*, 2000). This was probably due to the fact that patients tended to work on their preferred skills and use these skills routinely (Timmermans *et al.*, 2009). Patients suggested that when goals were set collaboratively, they were motivated and hence more willing to problem solve, persevere in the face of challenges, exert maximal effort, and were less frustrated with performance, and came to terms with their condition (Holliday, Ballinger and Playford, 2007; Henshaw *et al.*, 2011; Brown *et al.*, 2014). Benefits to patients' mental well-being (McGrath and Adams, 1999) were observed when patients spontaneously reported that goal-setting had helped them cope and reduced their fear, anxiety and depression at clinically significant levels.

Interventional studies commonly employed the principle of patient involvement in setting goals and worked towards these goals. In a study by Combs *et al*., (2010), patients chose five tasks using COPM for which they had intensive task-specific training which resulted in improvement in activity-based and participatory outcome measures (Combs *et al.*, 2010).

There were large effect sizes for Stroke Impact Scale (SIS) and perceived performance and satisfaction scores in COPM following intervention (ES 0.77-2.62) and at follow up after five months (ES 0.58-2.46). In yet another study using the client-centred activities of daily living (CADL) intervention, therapists established a working relationship to understand a person's lived experience (Bertilsson *et al.*, 2014). Following this, patients identified three goals for activities using the COPM and were taught the goal-plan-do-check (set a goal, plan activity, perform and then check performance) strategy. There was a significant improvement in the emotion domain of SIS in the CADL group compared to the non-intervention (without collaborative goal-setting) group (P=0.04), suggesting that establishing a therapeutic relationship and working towards patient identified goals could positively influence the emotional well-being and experience of a patient.

In a study using Botox injections in control and interventional groups, the achievement of patient-chosen goals was observed to be significant within both groups, but not between groups. This was despite the interventional group having high intensity therapy (HI) compared to usual care (UC) in the control group (Demetrios *et al.*, 2013). In a second study using Botox injections, patients negotiated goals for their upper limb function using the GAS tool (Nott, Barden and Baguley, 2014) and 90% of these patients had injections to the muscles relevant to their goals. Their GAS scores improved significantly ($z=4.02$; $p<0.001$) with an associated large ES (0.76). The greater goal achievements in these studies seem to be due to the patients choosing their goals and the ensuing motivation rather than the intervention per se. However the large ES should be cautiously interpreted, since the latter study has not reported confidence intervals.

In a block randomised controlled crossover study (Rotenberg-Shpigelman *et al.*, 2012) therapists set individualised goals in a collaborative goal-setting session using COPM and defined the personal and environmental barriers to achieving these goals. Neuro-functional treatment (NFT) was delivered. Significant improvements were seen in COPM scores after treatment in both groups, with large effect sizes. 78% of them achieved at least one of their targeted goals. However, only 26% achieved all targeted goals and SIS only improved slightly in both groups. In another block randomised control trial, patients in the intervention phase (phase B) participated in the goal-setting process by using a goal-setting workbook to identify participatory goals, had assistance of a keyworker to decide goals and participated in goal-setting meetings with professionals (Holliday *et al.*, 2007). Even though fewer goals were set in phase B, the proportion of goals found to be relevant and satisfaction with the rehabilitation process were significantly higher. There were no significant differences in proportion of goals achieved, length of stay or other functional outcomes between groups. Thus collaborative goal-setting, though it seems to have improved perception of participation and relevance, did not seem to have influenced achievement of goals in these two methodologically rigorous studies.

In a study using three single case experiments using the CO-OP program, personal goals were identified using COPM (McEwen *et al.*, 2009) and treatment goals for each session were negotiated between patient and therapist. Significant improvements were seen in most goals during intervention and post-test for all three cases. Using a similar approach for goal-setting and intervention in a second study, it was shown that the performance quality rating scale (PQRS) showed improved scores for all goals set by patients (McEwen *et al.*, 2010). COPM scores showed clinically significant improvement in satisfaction and performance for all goals except one. In another single case study, assessing effectiveness of motor imagery delivered

through tele-rehabilitation, the patient set individualistic goals for community ambulation (Deutsch, Maidan and Dickstein, 2012). Motor imagery scenarios and scripts were specifically constructed to address the patient's goals. There was a 57% increase in self-selected gait speed and 37% in fast speed and walking distance in six minutes increased from 257 to 277 metres. Though the above are single case experiments, improved goal-achievement was observed in all of the above studies compared to the trials. Better outcomes in single case studies suggest that, the individualised focus on interventions for patient-identified goals, which is possible in single cases, could be a significant factor contributing to goal-achievement.

Contrary to these findings derived from studies that adopted patient-centred principles, multiple studies revealed tensions due to setting goals using a non-patient-centred approach. The primary source of tension was the difference in scope of goals between patients and professionals. Professional goals were generic, focused on function, outdoor mobility, independence (Bendz, 2003; Alaszewski, Alaszewski and Potter, 2004; Boonstra, Wijbrandi and Spikman, 2005; Levack *et al.*, 2011) and activities of daily living (Cott, 2004). Patients, however, voiced goals related to highly valued activities but were outside the scope of professionals' practice or the rehabilitation context (Boutin-Lester and Gibson, 2002; Cott, 2004). In such situations, professionals often reformulated or reworded goals to fit in with routine practice (Parry, 2004), making them more specific, tangible and more like a contract (Hersh *et al.*, 2012a). It is possible that these differences in the scope of goals were due to goals being based on professionals' assessments (Rohde *et al.*, 2012), cautious predictions of recovery and system limitations like shorter hospital stays (Levack *et al.*, 2011).

Further tensions within goal-setting arose when therapists disagreed with patients in goal-setting meetings and steered the conversation away from a patient focus to a familiar area that fitted within the system (Levack *et al.*, 2011); some professionals appeared to perceive an undue weight being given to patients' and families' opinions (Elsworth *et al.*, 1999). Moreover, if therapists perceived that families set goals focused on agendas different to theirs, this led to disengagement with families (Levack *et al.*, 2009). Above all, when there were disagreements between patients and professionals over goals, professionals suggested that patients were supposedly stuck in the stages of acceptance and set unrealistic goals based on the bereavement model. If patients failed to engage, professionals became frustrated and attributed this lack of engagement to lack of motivation (Huby *et al.*, 2004). Eventually these tensions led to breakdown in therapeutic relationships (Alaszewski, Alaszewski and Potter, 2004).

It is possible that tensions were due to patients viewing rehabilitation as response to the situation they were in (Alaszewski, Alaszewski and Potter, 2004; Brown *et al.*, 2014) due to which they adopted a responsive, proactive and dynamic approach to the future. Contrarily, professionals had an accepting and adaptive approach to the future (Alaszewski, Alaszewski and Potter, 2004). However the enthusiasm and motivation in patients' opinions might be a reflection of the mood of the group and socially desirable responses from Brown *et al*' s (2014) focus groups.

2.9 Summary and conclusion

The systematic search and review to scope out the extent, nature and effects of PCGS revealed that it was adopted to a limited extent in routine practice with very few professionals

being totally patient-centred (Leach *et al.*, 2010). The findings revealed that goal-setting was the professionals' prerogative with limited patient-centred principles. In extreme examples there were no structured goals expressed by patients or professionals and no strategies were written to achieve patient's goals (Bendz, 2003). However, most of these studies used single methods to investigate the process, calling into question the dependability of their findings, but the integration of the findings in this review from these various studies using different methods has helped the process of corroboration.

The review also revealed that there was an increasing application of patient-centred principles in interventional research which showed improved outcomes with moderate to large effect sizes in achievement of goals, psychological well-being, satisfaction and some function. However these findings were based on studies ranging from moderately rigorous to weak methodologies some with reporting biases. Overall there were potential positive implications for adoption of PCGS, but without strong evidence and inadequate information to operationalise PCGS in practice. It was also clear that there were multiple facets to this approach and currently only isolated aspects have been applied and researched. Thus, the overarching research question for this research (section 1.8), about the influence of PCGS on outcomes could not be answered from the literature. Neither did the literature report any predefined methods that had employed patient-centred principles in a comprehensive manner. On the other hand, potential principles and strategies have been identified that could help build comprehensive methods to implement PCGS.

Based on this greater understanding of the concept of PCGS, its application, its outcomes and the major gaps in research and wider practice, subsequent studies were designed for this research. It was considered important to explore local practice to compare similarities and

differences with wider practice. Moreover, the major gap identified in literature was the lack of comprehensive structures to apply principles of PCGS within stroke rehabilitation. Hence this research focused on exploring local practice and also developing a new resource for applying PCGS. The methodology for studies that followed this review is described in Chapter three. The empirical study (Study one) to understand local practice and compare it to wider practice and subsequently to build a resource to apply PCGS in practice is reported in Chapters four and five respectively. The knowledge derived from this literature review was integral in designing the studies and building the resource for PCGS.

CHAPTER 3

METHODOLOGY

3.0 Overview of chapter

Although the design of a study has no fixed starting point or course it is crucial that any method that is finally implemented for research follows from a critical evaluation of all available methodological approaches (Maxwell, 2005, p.63; Crotty, 1998,p.14). Various design and methodological issues were initially considered to provide direction to this research and to address the questions posed. This chapter aims to describe the methodological considerations underpinning this study, based on the researcher's epistemological and philosophical orientations. Further, it will outline the theoretical perspectives underpinning the study. The specific methods of data collection and analysis for the empirical studies will be described in chapters four and six pertaining to the individual studies.

The findings from the different studies within this research influenced the evolution of the research questions and the design along the research process. Hence an overview of the findings from the literature review and the empirical studies are presented in the section 3.1 to illustrate the logical development of the research questions for this research.

3.1. Evolution of the research questions, aims and objectives in the various stages

The methodology for a study is largely influenced by the research questions (Robson, 2002, p. 80). This study adopted an emergent design, which was set out in three stages, to address

different aims with matching methods and is illustrated in figure 3.1. The different aims and objectives corresponding to the three stages and the multiple research questions are outlined below. Initially a broad, 'overarching research question' founded on the background reading around the study focus was defined (chapter 1, section 1.8, p 27) and was stated as:

What is the influence of patient-centred goal-setting in current stroke rehabilitation practice on outcomes relevant to the patient and the practitioner?

In order to answer the overarching research question, smaller, more specific sub-questions were defined.

Sub-questions 1, 2 and 3:

- *Is goal-setting in stroke rehabilitation patient-centred?*
- *How is it implemented?*
- *What are the potential benefits of such a process for the patient and the practitioner?*

The aim and objectives to answer these questions were stated as:

Aim 1 (corresponding to Stage 1 in figure 3.1): To explore whether goal-setting practices in stroke rehabilitation are patient-centred, what methods are used and with what outcomes:

a) in the literature and
b) in current local practice

Objectives for part a) of aim 1:

a) To conduct a systematic review of the literature in order to:

- systematically search, evaluate and summarise the evidence related to PCGS in stroke rehabilitation

- gain understanding of such practices around the world and

- identify gaps in research in the wider context.

A systematic review was conducted in the first stage to meet the above objectives (Chapter 2). This revealed that PCGS was practised only to a limited extent in the wider neuro-rehabilitation and stroke context around the world. There was insufficient background knowledge in the published domain about the patient-centred approach to goal-setting process. The review did not reveal comprehensive mechanisms underlying such a process or explicit methods for implementing PCGS with patients who had a stroke. The effects of PCGS were minimally described. However, some strategies that could help build new methods, and theory to underpin these methods, were identified. The review also showed that the concept of patient-centredness was multidimensional and any further work required a consideration of the complexity of the concept. Hence a preliminary conceptual analysis was carried out to define its dimensions and components (appendix 3.1). This analysis further resulted in a framework which was used to analyse data for parts of this research.

Though the systematic review revealed that wider practice was limited in adoption of patient-centredness in goal-setting, the researcher did not assume the same would be the case in the local study setting. In case the current local practice was found to be better in applying PCGS, then the research question about outcomes of such a practice could be examined. If found to be otherwise, then barriers and challenges specific to the local context and strategies applicable to this context needed to be understood. Therefore an exploratory and descriptive

study of current practice was designed to understand local practice and provide strategies to develop new methods for PCGS. The objectives for the first empirical study were set out as follows.

Objectives for part b) of aim1:

b) To conduct an exploratory study in local practice in order to:

- find out whether patient-centred principles were implemented in goal-setting in local practice
- understand the processes in local practice including the barriers, facilitators and effects of patient-centred goal-setting process
- identify ideas, principles and tools that will help to construct a method to make goal-setting process more patient-centred.

The first empirical study involved multiple case study design utilising interviews, observation and document analysis (figure 3.1). Focus groups were additionally conducted in this first stage to collectively explore and generate knowledge regarding strategies, principles or rules that provide the basis for a PCGS method (figure 3.1).

The findings from this study are discussed in detail in chapter four. However, one key finding was that the local practice did not employ comprehensive PCGS methods. However, the study participants suggested several strategies to help make goal-setting to be more patient-centred which could inform the development of resources to bring about the above change.

It was clear at this stage that the initial overarching research question could not be answered. The lack of operationalisation of PCGS in practice meant that the influence of such a process

on outcomes could not be studied. Hence the researcher had to take a step back and modify the overarching research question. It was restated as Research Question 2.

Research Question 2: Can a feasible and valid method be developed and applied to make goal-setting for stroke rehabilitation more patient-centred?

The aim and objectives were stated as follows.

Aim 2 (corresponding to Stage 2 and Stage 3 in figure 3.1):

To

a) develop a new method/resource to implement patient-centred goal-setting,
b) implement it in practice and
c) test its appropriateness and feasibility in stroke rehabilitation practice

Objectives:

a) To integrate knowledge from literature and practice to:

- develop a resource in the form of a toolkit that can help practitioners be better able to deliver PCGS

b) To facilitate the application of the newly developed patient-centred resource within the study setting in order to:

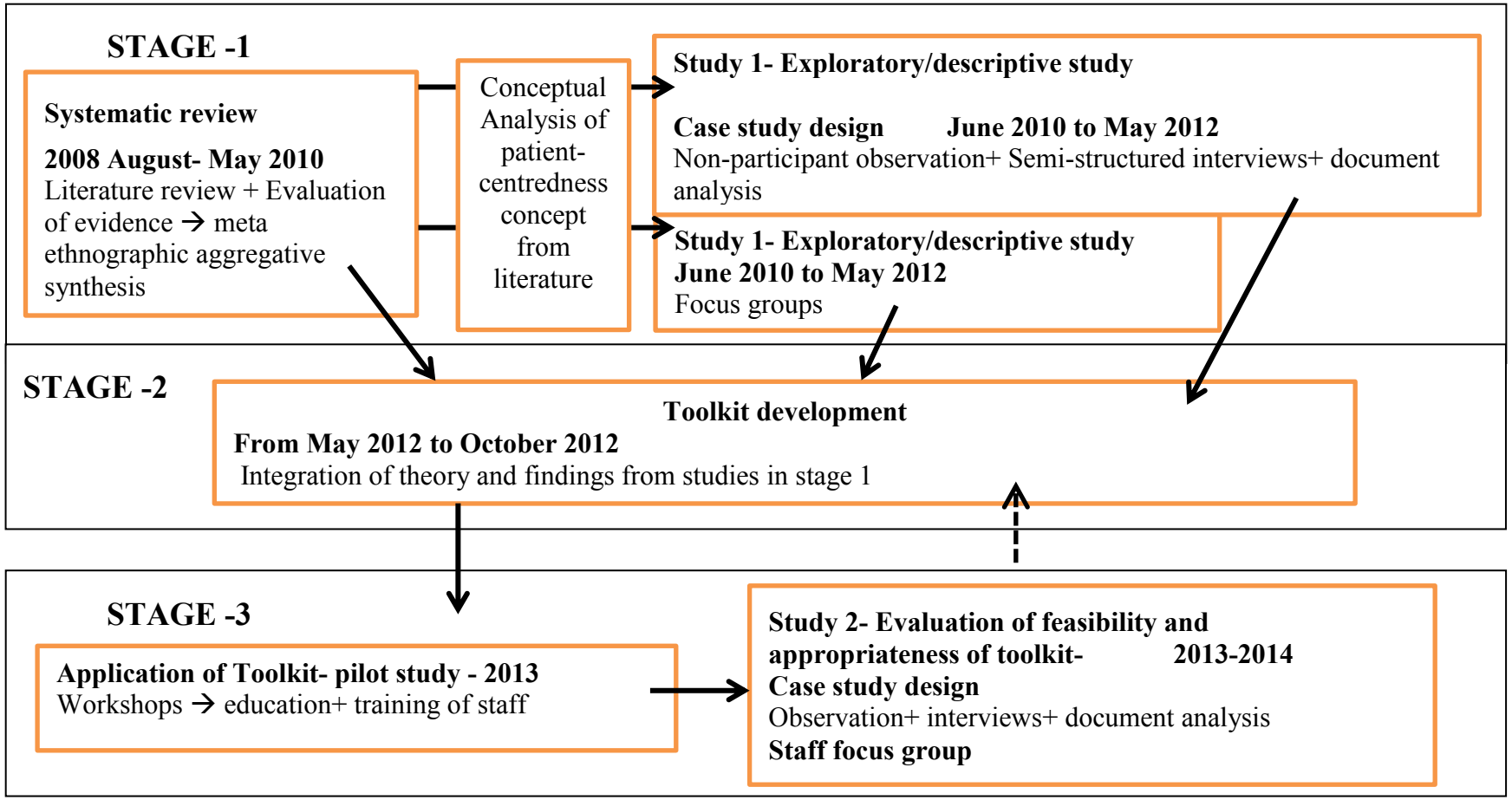
- create awareness and educate professionals by providing training and support to adopt the new resource for goal-setting

c) To conduct a small scale pilot study locally to:

- evaluate the feasibility of applying the new resource in practice
- evaluate whether the new resource is appropriate to improve patient-centredness in goal-setting
- identify potential outcomes resulting from the application of the resource

In the second stage, information from the literature (Chapter 2) and findings from the first empirical study (Chapter 4) guided development of a toolkit for PCGS (Chapter 5). Once this resource for applying PCGS was developed, the third stage involved strategies to create professional awareness such as education and training. The toolkit was then piloted in a small sample of patients, using case study design, to evaluate for feasibility and appropriateness (Campbell *et al.*, 2000), the results of which are described in Chapter six.

Figure 3.1: Flow diagram of the different stages of the study and the component methods.



Thus the aims and objectives derived from the different research questions required various approaches and methods. These approaches and methods were not just determined by the questions but also by the epistemological orientation of the researcher and theory underpinning the research, discussed in section 3.3.

3.2. Choice of research branch

Due to the researcher's background as a physiotherapist with a special interest and experience in stroke care and research, the focus of this project is on the quality of care (experience and outcome) for people with stroke, the efficiency of processes to cater to patients' needs and structures that support a patient-centred approach in stroke services. The researcher opted to examine a key process (i.e. goal-setting) within the delivery of stroke rehabilitation in the NHS in the UK. Hence this study is considered to be within the remit of Health Service research (Bowling, 1997, p. 6).

3.3 Researcher's epistemological orientation, ontological basis and research approach

Goal-setting is a complex phenomenon influenced by the social and psychological attributes of participants involved in the process (Scobbie, Dixon and Wyke, 2011). An aspect of studying this process involves studying the perceptions and knowledge of stake-holders which is incompatible with any attempt at complete objectivity (Kolakowski, 2004, p 7). Knowledge and perception about a complex phenomenon such as goal-setting cannot be derived based on direct and measurable observations and does not lead to a single truth (Crotty, 1998, p. 18); rather it requires an examination of peoples' unique experiences, and multiple realities. Since

we are studying goal-setting in the complexity and multiple influences of the real world, we cannot always confidently assign it a specific cause or effect. Thus, the goal-setting process cannot be isolated from other confounding processes such as diagnosis, critical care and integrated service provision that possibly influence healthcare outcomes. Moreover, considering the influence of the researcher's outlook, background, experience and critical perspectives, data interpretation cannot be value free. Due to the lack of substantial evidence surrounding the current topic, development of hypotheses or testing hypotheses based on theory using quantitative methods was not possible. Subsequently, the epistemological tenets of positivism were disregarded for this research and the focus was shifted to the relativist approaches on the other end of the continuum of approaches (Patton, 2002, p. 579).

The professionals and patients interpret goal-setting and patient-centredness within their frames of meaning as they engage with it, thus giving rise to multiple realities. The design and methodology should help understand such multiple realities by getting inside the context and eliciting the meanings from the participants (Creswell, 2013, p 17). This could be aptly studied using the relativist approach since this approach emphasises study of the entire complexity of events. The approach would be useful to understand the meaning of experience, in this instance the patients' experience of goal-setting and help understand behaviour, such as participating in the process (Grbich, 1999, p.8). The data, to explain such multiple realties and behaviours, needs to be qualitative. Qualitative approach has been critiqued for its demands on the researcher to be open, flexible and engage in complex procedures for data collection and analysis. Most often the small sample size and non-generalisability of data are critiqued (Howard and Davis, 2002). However, it was decided that the data collected would be exhaustive to reflect the depth and complexity of phenomenon with the use of multiple sources of data.

The process of goal-setting, within the specific context of stroke rehabilitation is influenced by the interaction of multiple factors such as personal beliefs, life situations, the culture of the NHS and organisational structures. “The facts”, here, are not always objectively available: rather they are a reality in the social world which is constructed and played out by the social actors, i.e. professionals and patients in the healthcare system in this case (Constructionism) (Crotty, 1998, p. 42; Ponterotto, 2005). A social constructionist approach could help to identify the multiple interactive factors such as communication, documentation, working pattern etc., that influence goal-setting (Patton, 2002, p. 96; Ducharme and Trudeau, 2002).

The construction of this reality must understand the meanings as perceived by the actor and view them from the standpoint of the participants in a process known as interpretivism (Blaikie, 2007, p.131). For example within the rehabilitation unit the patient might view themselves to be of a lower standing than the professionals due to their lack of expertise, and hence they might participate to a lesser degree in planning for their rehabilitation (Cott, 2004). An interpretative approach could allow us to observe behaviours that illustrate limited participation (e.g. the patient does not seek out the professional) and understand participants’ perspectives, interactions and opinions effectively using qualitative methods. This approach allows interpretation with a degree of latitude not permitted with a more positivist approach. But, iterative and inductive analysis methods commonly used for qualitative research can be misconstrued as subjectivity in analysis and lack of rigour in research conduct. To counteract this critique, the scientific rigour within this study was ensured by employing measures for improving credibility, applicability, dependability and confirmability (Miles and Huberman, 1994, p. 2) highlighted in methods sections (4.1 and 6.1) of chapters four and six.

The evolution of the research focus as indicated in section 3.1 suggested that explicit methods for PCGS were required. At this point, the researcher's epistemological orientation for the refined focus was deliberated. The researcher's social constructionist approach emphasised collaboration, co-construction and positive visioning, and also helped to redirect inquiry towards change (Walker and Dewar, 2000). The research participants were engaged in discussions to contribute to development of the toolkit and in collaborative learning, to gain awareness about current practice in order to drive change in practice. Thus the researcher adopted a social constructionist stance throughout the entire study.

Social constructionism generates theory that is specific to the study context, in this instance, goal-setting in stroke rehabilitation. This theory will therefore be limited in its ability to explain the effectiveness of being patient-centred in other contexts such as out-patient consultation (Mills, Bonner and Francis, 2006). The limitation with generalisability of findings from this study was acknowledged, but, direct extrapolation of findings was not the intention of this study. Rather, it is proposed that the theory from this research can be applied to a wider context if a higher level of abstraction is used (Mills, Bonner and Francis, 2006). For example if a high level of theory abstraction from this study results in principles for implementation of patient-centredness, these principles can be adapted for a different context such as consultation in a general practitioner's practice. Moreover, transferability of findings to contexts similar to this has been enhanced by rich description of the context in section 4.1.2.

In summary the researcher acknowledges that a constructionist stance will not help to prove cause-effect relationships and will only produce context specific theory. Nevertheless this approach is necessary to map out the complex multiple realities of the goal-setting process

and to generate foundational theory that is limited in this field using a qualitative approach (Creswell, 2013, p 47; Young and Collin, 2004).

3.4 Theoretical stance of the researcher

As discussed above, interpretation of reality will be influenced by researcher biases which can be made explicit through a reflexive process. Making explicit the researcher's awareness of her theoretical stance and being critical about this stance improves reflexivity (Silverman, 1998 p. 102). Hence different theoretical approaches were considered. Theories subscribing to the interpretative philosophy were considered. The action theory of society suggested that society is produced when its actors orient their actions to one another by acknowledging shared beliefs, values and interests (Seale, 1998, p 28). Action theory, however, makes claims about the potential for a "science of action" which can be empirically verified, and this study does not seek to make this kind of claim. At the stage of planning it was implausible for the researcher to foresee whether the theory generated by the study would explain the cause of their actions and beliefs. Symbolic interactionism suggests that the symbols (language) and gestures that humans share to interact with each other produce the social world. Rational understanding of the actors' world required interpretation of the actors' meanings in both theories. Therefore what patients and professionals believed, specifically on the question of being patient-centred in goal-setting, needed to be interpreted. it is possible that people behaved in particular ways that symbolised the groups' norms or their own particular beliefs and attributes (Seale, 1998 p 29). The review revealed that professionals behaved in certain ways due to their shared beliefs, for example they were not consistently patient-centred in goal-setting because most of them believed that they already were patient-centred

(Rosewilliam, Roskell and Pandyan, 2011). Thus, symbolic interactionism could have explained shared beliefs and behaviours. But symbolic interactionism, in its strictest sense, cannot easily account for such external demands and constraints as those imposed by institutions on the process of goal-setting.

The researcher concluded that it was inevitably important for the study to have a theoretical basis which could be fairly clearly defined – but that strict adherence to any single approach was not entirely responsive to the complexities of the data. Thus, in the end, a broadly critical realist approach was adopted, since this – once again – seems to allow a degree of flexibility. This approach is usually defined as lying somewhere along the continuum between positivist and relativist theories. "Reality" is a social and historical product (Grbich, 1999, p. 16). This seems to be the case in healthcare where the principles and processes suggested for quality of care, such as patient-centred practice, have resulted from practice evolution and social research evidence (Leplege *et al.*, 2007). Similarly, social theory, according to critical realists, should be transformative based on the explanatory critique of social processes (Mingers, 2006). The current research intended to generate theory in relation to PCGS and explain the interaction of factors influencing it: and in doing so it aimed to produce just such an explanatory critique. Moreover this research intended to empower the participants in that the patients and professionals would work collaboratively to augment the patient-centred process by developing a new method (transformative), which again, the researcher believed, indicated her critical realist position. From the perspective of the researcher's philosophical stance of social constructionism, collaboration with participants, their engagement with the research process, and gaining awareness as discussed in the above section were satisfied by the critical realist theory. Constructionism and realism seem to be the 'two sides of the same coin' (Walker and Dewar, 2000).

According to this theory there were complex interactions between dynamic structures giving rise to generative mechanisms that create the social processes. For example, the working of the multidisciplinary teams could be generating tendencies and behaviours that influence the patient-centred practices within goal-setting. With a critical realist perspective, the researcher attempted to identify the generative mechanisms and underlying structures to describe practice with a critical viewpoint.

The researcher acknowledged the emancipatory role of the research during the conduct of the study and hence transformatory steps such as an attempt to develop a method of PCGS was undertaken. A 'bottom up' approach was developed by working with the practitioners and patients to identify solutions and ideas for bringing about change. This new method needed to incorporate specific 'structures' such as documents that encouraged patient participation or environments conducive to participation (Monaghan *et al.*, 2005). Additionally the new method needed to consider 'mechanisms' such as collaborative team working that could influence the behaviour of patients and professionals (Monaghan *et al.*, 2005). Such an approach to modify the structures and mechanisms operating at different levels (for example: individual's motivation at micro level and the organisational resources at macro level) is integral to critical realist approach and hence its adoption was further justified.

The critical realistic approach is not without its limitations. Creating awareness about practice would not automatically cause people to change behaviour as they might have other influential beliefs (Hammersley, 2009). The mechanisms considered to cause practice to be less patient-centred cannot be easily eliminated or changed in a complex setting such as healthcare. What should be changed in practice could be a value laden decision. Even if new structures are imposed, due to complex interactions they might not work as intended (Sayer,

1997). Despite a consideration of these limitations, critical realist theory was adopted as the theoretical lens through which the researcher studied this issue just so that possible explanations can be derived.

3.5 Research design in the different stages

As discussed in section 3.1 the focus of this research was iteratively developed based on the findings of the previous studies. Nevertheless, as the study evolved, the theory, questions, methods and sampling strategies were kept interrelated and compatible to each other during the study's various stages (Robson, 2002, p. 82). Details of the design for the empirical studies in the different stages will be discussed below.

3.5.1. Stage 1: Exploratory and descriptive study

3.5.1.1. Case study design

For this stage an exploratory scoping exercise was designed to meet the objectives. The key requirement within the design was the ability to gain understanding from the perspective of the individuals involved in the goal-setting process (Bowling, 1997, p.114; Wade, 1999). Different research designs were considered for this purpose.

Despite establishing a literature base for the focus of the study, from which pertinent variables could have been identified for a survey, this was not considered as a suitable method as the breadth and depth of interactions between the multiple variables cannot be captured using a survey. The numbers of respondents within the local site were limited. Moreover just surveying an issue such as patient-centred practice could result in biased responses due to

respondents' moral, professional and ethical obligations and responses might not be a true reflection of their practice which cannot be corroborated (Powell, 2014, p 186).

For similar reasons, an experimental design was not considered. Nor were there well-defined PCGS methods that could be implemented and evaluated as a part of an experiment. The variables identified by the literature and previous study were not mutually exclusive and had restricted outcome measures for such a process, specific to goal-setting. Hence experiments generally were ruled out. For similar reasons quasi-experimental designs were considered feasible only if theory was developed further and a complex intervention developed to operationalise PCGS. In other words, all such designs seemed clearly not fit for purpose (Campbell *et al.*, 2000; Craig *et al.*, 2008).

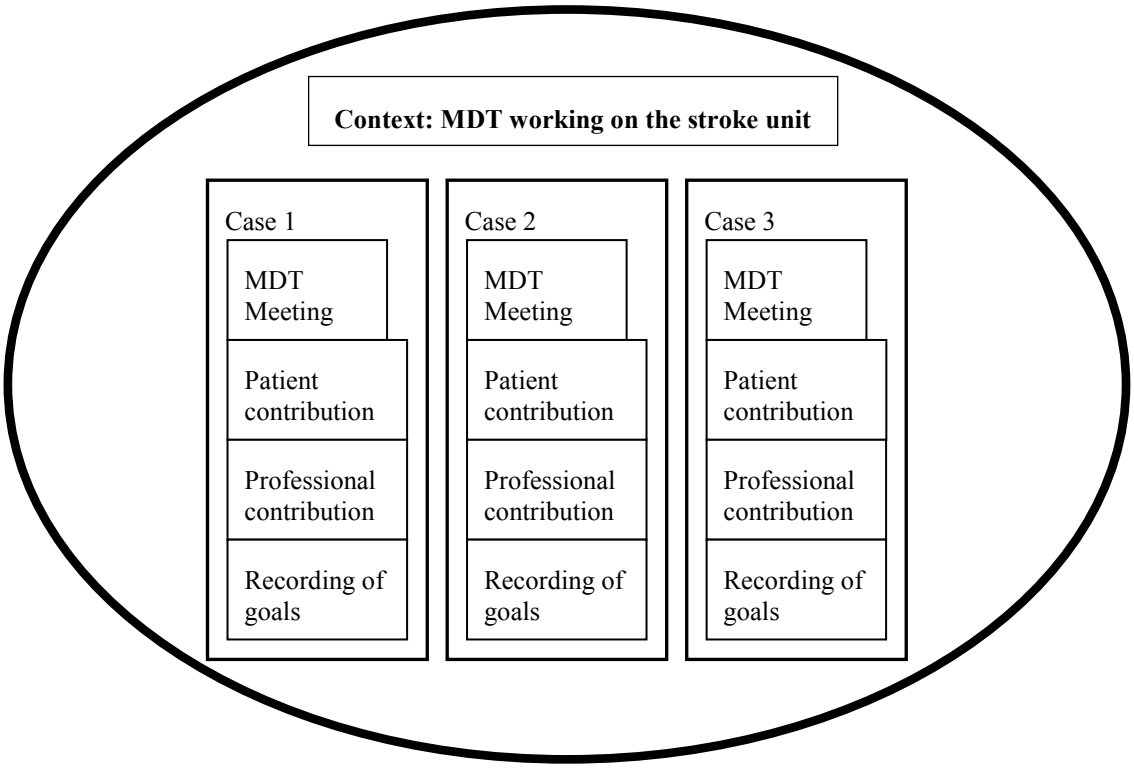
Analysis of documents or archival analysis method would have ruled out respondent bias and was feasible within one site; however, the complex interaction of factors that affect PCGS and strategies for future practice cannot be acquired from using this method. The need to study goal-setting in the context of multidisciplinary working without controlling the events, and examine the complex interactions between the patients, professionals and system during goal-setting, led to consideration of ethnography and case study method. Ethnography required long term immersion of the researcher in the setting which tends to influence natural behaviour of participants or the researcher could go 'native' (Robson, 2002, p.186), therefore, this strategy was discarded. Moreover, the feasibility of spending long periods of time and impromptu questioning on site which are important in ethnographic studies was not ethically or pragmatically feasible in the healthcare setting. A case study was considered more appropriate as it retains holistic and meaningful characteristics of the goal-setting event (organisational process) within the real life context (organisational structure). Hence the

decision was made to effectively study the process and the context using a case study design (Yin, 2003, p. 13).

A multiple case study design was chosen so that data can be collected from many cases and compared across these cases (Yin, 2003, p.46). It is important to note that a larger number of cases does not indicate increased generalisability to the population, as seen in statistical generalisability, and hence a small feasible sample of cases was studied within the two studies. Considering the limited generalisability of findings from such a design, it was thought best to use analytic generalisation and use higher level of abstraction to generate theory; therefore 'what is transferable between cases are not lumps of data but sets of ideas' (Pawson and Tilley, 1997, p. 120).

Each case was defined as 'goal-setting for an individual'. Every case within the study included further subunits of analysis (depicted in figure 3.2) such as MDT discussions regarding goals, patient and professional contributions to goal-setting and recording and review of goals. These sub-units were chosen to be scrutinised to give a greater insight into the process and holistically study the entire process of goal-setting. One aspect, i.e. interaction between the patient and the professional during therapy sessions, was left out in this study since a previous study that involved observations of interactions during therapy sessions had shown that goal-setting is not routine during these sessions (Parry, 2004). In addition to this uncertainty of occurrence, logistical issues of scheduling observations of patient-therapist interactions during therapy time resulted in not including this sub-unit of goal-setting. Each of the sub-units was studied using appropriate methods discussed in chapter four.

Figure 3.2: Embedded Multiple Case study design showing examples of units and sub-units



3.5.1.2 Focus group

Collective reasoning within the stakeholder group was essential to identify what they considered important for such a PCGS process (Bowling, 1997, p.352). Since they were experts in their own areas and had better insight into issues with their goal-setting process, it was decided to gain access to their knowledge and preferences for building a new method using focus groups. Moreover implementation of change in group processes such as goal-setting would be effective if the stake holders were empowered as a group to contribute to the proposed changes (Schein, 1996). Therefore focus groups were conducted to supplement the case studies within this work and described in chapter four.

3.5.2. Stage 2: Toolkit development

As discussed in section 3.1 the study evolved to bridge the theory-practice gap by developing a new resource to enhance patient-centredness in goal-setting. It was in the form of a toolkit with rules, ideas, principles and tools accumulated from the review and studies in stage 1. Toolkits have been recommended to facilitate the introduction of innovative practices by the NHS Institute for Innovation and Improvement, (2006-2013) in line with changes in department of health (DoH, 2010) policy. The researcher primarily carried out the construction of toolkit, but the local clinical leaders considered the pragmatic aspects and feasibility of the toolkit (Cahill *et al.*, 2010). They were also involved in setting up the application of the toolkit as they were the gatekeepers for change and could also facilitate its adoption from within the team.

3.5.3. Stage 3: Application and evaluation of feasibility and appropriateness of toolkit

3.5.3.1 Case study design

The ultimate outcome of research is its benefit to the researched population and therefore its pragmatic application (Green and Seifert, 2005). Hence there was a need to evaluate the toolkit for its appropriateness or the ability to achieve the purpose for which it was developed i.e. whether the toolkit improved patient-centredness in goal-setting. Moreover, the feasibility of its application within the practice also needed to be evaluated.

The research strategy at this stage involved training and education of the staff to facilitate application of the toolkit. It was believed that participant reflection would increase awareness of issues, need for action and therefore change in practice (Gallagher, Londrigan and Levin, 2009). The researcher played the role of the facilitator in the study settings along with the clinical lead in the research setting, who guided decision making during the various stages of research. The researcher organised and carried out in-service training programmes and workshops for the staff volunteering to participate in this study. Further details of the steps involved in development and application of the toolkit in this setting are described in chapter five and six.

This evaluative study was not set out to measure the outcomes of the toolkit as in conventional evaluation studies but to assess whether it achieved the purpose of making the goal-setting process to be more patient-centred. However, the potential benefits of

the toolkit for the patient and professional were scoped out. Yet another purpose was to collect data to refine the toolkit for future use (as indicated by the dotted arrow in fig 3.1). A small scale pilot study based on a multiple case-study design and methods, similar to Study one, was done but with emphasis on feasibility of application, to identify pragmatic issues and evaluate the toolkit. This Study two consisted of data collection relevant to the input (application of the toolkit), process (interaction between personnel and patients, quality of relationship, communication) and potential outcomes (effectiveness in relation to participants) (Bowling, 1997, p. 41) and are reported in Chapter six.

3.5.3.2. Focus group

One focus group was conducted with staff who applied the toolkit for evaluation in order to identify the factors related to feasibility, potential effects of its application and strategies to refine its use. Further details of each specific method for data collection for stage three will be presented in chapter six.

3.6. Theoretical propositions underlying analysis

An understanding of the theory in this area of research largely influenced the research objectives. This understanding was set out as the theoretical propositions that further guided the analysis and interpretation of data in this study (Yin, 2003, p 130). These propositions can be summarised as follows:

- Patient-centredness is a multifaceted approach and research had previously applied isolated aspects of this approach in goal-setting.

- To enable a holistic investigation of patient-centred approach, the complexity of the concept had to be broken down to ensure all aspects were studied in this research, so, to begin with, these dimensions and their multiple components were identified from literature, analysed for their meaning and their boundaries were defined in a conceptual framework (appendix 3.1).
- It was found that, 'patient-centredness' involved four main dimensions relevant to goal-setting: clinician establishing a therapeutic relationship with the patient, empowering and sharing responsibility with the patient, identifying and catering to a patient's individual needs and ensuring all aspects of their health problems are attended to (Mead and Bower, 2000; Ozer and Kroll, 2002; McCormack, 2003; Leplege *et al.*, 2007). Further details of use of these dimensions and their components from the conceptual framework will be described in sections relevant to analysis within this chapter and interpretations within chapters four and six.

The data analysis primarily used a deductive approach wherein the theory relevant to the concept of patient-centredness i.e. the conceptual framework was used to analyse the data to: a) explore the extent and nature of patient-centredness in practice in Study one and b) evaluate whether there was better adoption of patient-centred principles following the application of the toolkit for PCGS in Study two. Additionally, the data also generated new insights which were derived by induction. This inductive approach was also adopted to derive ideas from the studies to build and evaluate the feasibility of applying the toolkit (Pope, Ziebland and Mays, 2000).

3.7. Ethical considerations and Patient and Public Involvement (PPI)

The ethical principles of respect for autonomy, beneficence and justice were upheld during the conduct of the research, the details of which are discussed in table 3.1. No major ethical concerns arose during the conduct of the research. Service users (people with stroke but not in active NHS care) were consulted during the research design stages of both studies (evidence in appendix 3.2). As a result of service user involvement research ideas were refined and modifications were made in aspects such as the participant information sheets.

Table 3.1. Consideration of ethical principles and strategies put in place to support them

Ethical Principles	Relevant ethics document	Strategies to support ethical principles within this research
Informed consent	Appendices 3.6a to 3.9b Study information sheets for patients and staff Consent forms for patients and staff.	• Participants were given multiple opportunities to understand the research project from both the printed information sheets and from discussing the information with the researcher. • Patients were informed that they could discuss the research with their family and staff who cared for them. • Contact details of the members of research team were left on the information sheets so that they can contact researchers if they had any queries or issues about the research. • Screening and approach for study by the researcher external to the institution caused little or no pressure on staff or patients to get involved in the study. • Informed written consent was taken from all patient and staff participants and copies were left in the notes, given to the patient and kept in researcher's records.
Confidentiality	Appendices 3.6a to 3.9b Study information sheets for patients and staff Consent forms for patients and staff	• The written information assured participants of confidentiality of their information and their data, safety of the data and anonymity of quotes used for writing up. • During observation of the team meetings, in order to protect confidentiality of data for these non-participants, it was arranged with the leader of the meeting that, participant patient's case will be discussed first. The researcher then left the room so that other patients' information was not accessed by the researcher. • After data was collected, their personal details were blacked out in files. Participant names were replaced by alphanumeric codes. • In writing up for publication, personally identifiable details were not presented

		to the public. • Data was stored on password protected computer and accessed only by the members of the research team.
Beneficence	Appendices 3.6a to 3.9b	• The patients who were approached were informed that there were no risks due to participation except that recollection of stroke could cause them stress. • They were informed that data collection will be stopped temporarily or discontinued if they found it stressful. In case anyone was stressed arrangements were made to refer to clinical team lead as recommended by the ethics committee. • Patients were informed that the research will not have any direct benefits but will help improve services for the future in Study one.
Justice	Appendices 3.6a to 3.9b Study information sheets for patients and staff Consent forms for patients and staff.	• Patients with diminished mental capacity were not recruited for this study as they would not be able to participate in the research process. • Since the study was carried out in acute settings where patients had frequent interaction and interventions, their contribution was kept to the required minimum. • They were not repeatedly interviewed for clarifications or data saturation to limit their burden of participation. • It was further agreed with the other researchers on the ward, that if a patient participated in other interventional trials which needed close monitoring for side effects or two other less intrusive trials, then they would not be approached for this study by the researcher. • Participants were assured that they could withdraw participation any time after consenting and this will not affect the care they receive from the NHS.

3.8. Summary of chapter

This chapter outlined, critiqued, and justified the proposed theoretical and methodological strategies adopted for the research. The methodology designed to meet the research objectives incorporated strategies for rigour and flexibility at every step of the research process. The specifics of methods for data collection and analysis will be presented within chapters that describe the individual empirical studies along with their findings.

CHAPTER 4

STUDY ONE

4.0 Introduction

The literature review identified that PCGS was limited in wider practice and barriers to why this might be. Strategies to improve practice were also identified from the literature. However, one could not assume that local practice would be similar to wider practice. Hence Study one was designed to explore whether patient-centred principles were applied in goal-setting in local practice, to understand the barriers, facilitators, principles and strategies to operationalise PCGS and its effects. This chapter will present the methods used for data collection, data analysis, the findings relevant to the above aims and discuss key findings within wider literature.

4.1 Methods

In Study one, within the overarching case-study design (discussed on page 77), a multi-method approach was used to gain a better understanding of the complex data representing varying perspectives (Lingard, Albert and Levinson, 2008). The data was collected from the patients and the professionals using interviews and focus groups. Team meetings were observed and case notes were analysed to corroborate information provided by participants. Using multiple sources helped to study the goal-setting process holistically and in greater depth.

4.1.1 Ethics

Ethical approval was obtained for Study one from the Black Country Local research ethics committee (LREC Refno.10/H1202/56-appendix 4.1a). The Birmingham Clinical Research Office granted approval for conduct of the research and access to research site (ref nos. RRK4085-appendix 4.1b).

4.1.2 Setting and routine goal-setting practice

The study was conducted in the acute stroke rehabilitation unit of a University teaching hospital in a city in England. It was a part of an NHS trust that served a large multicultural population within the West Midlands. The stroke unit was a busy ward with 36 beds. Patients, suspected to have had a stroke, were admitted to the stroke ward from the hospital's accident and emergency unit or other wards in the hospital. The length of stay for all admissions was on average 20 days. Patients who survived, on average were either discharged home after 14 days or transferred to the subacute stroke rehabilitation facility in another trust after seven days. The staff in the acute stroke unit communicated regularly with staff in the subacute rehabilitation facility regarding the patients' condition especially close to their transfer date.

In the acute stroke unit where this study was done, patients were cared for by staff who worked as a team that could be best described as multidisciplinary in nature. The team included doctors, physiotherapists, occupational therapists, speech and language therapists, nurses, dietitians, social workers (who were involved but not part of hospital team) and specialists. The structure and composition of the stroke unit was on a par with effective stroke units around the world (Langhorne and Pollock, 2002).

Goal-setting was a routine part of the care delivery as recommended by guidelines (ISWP, 2012). The routine, as reported by the clinical consultant physiotherapist who was also a collaborator for this research, was that patient views were sought by the staff during their assessment sessions and goals were set for the patient during the therapy session. The information gained from assessments and conversations with the patient were brought to the weekly 'MDT meeting' of the healthcare team for discussion. Goals were also set considering the views of the relatives of the patients.

The representatives from different health professions also went around as a group to visit patients in their beds once every week to communicate with them and their carers. They discussed goals, interventions, progress and issues with each patient. Usually this 'ward round' took place on a Monday morning and finished by lunch time. Then the team met on the Monday afternoon for the weekly MDT meeting.

Notes from the team meeting were recorded in patients' case notes in a form called the MDT goal-setting document. Professionals also documented their assessments and goals in different 'profession-specific documents' or in the common case notes which had sheets titled 'continuation sheet'. Thus the process of goal-setting was complex with multiple interactions, levels of decision making and record keeping which required the use of multiple sources of data for a holistic understanding of the process.

4.1.3 Participants

The sampling strategy for screening and recruitment purposes was mainly purposeful criterion based sampling (Patton, 2002, p. 238). It was purposeful since the researcher's purposes could be fulfilled only if the participants had certain attributes to be able to contribute to the

research. These attributes were defined as the inclusion and exclusion criteria (table 4.1). The sampling for documents was exhaustive as all documents within the case notes that had plans for care or goals for rehabilitation were included.

The sample sizes for the study were based on pragmatic reasons rather than aiming for data saturation. In the goal-setting context, patients' needs and goals and what patient-centredness meant, to participants, could be "potentially-limitless" categories (constructionist view of multiple realities and meanings) and hence data saturation was not aimed for (Green and Thorogood, 2009, p.120). Additionally, there were only a limited number of staff working at the study site who could be recruited which determined sample size. With regard to repeated interviews with participants, this was not possible in an acute care setting due to quick turnover of patients, busy work schedule of staff and causing undue and unethical research burden. The health research governance in NHS requires sample size to be declared at the outset. So it was decided to have a feasible sample size, and not continue recruitment until data saturation was achieved (Mason, 2010).

Table 4.1. Inclusion and Exclusion criteria for patients, staff participants and documents.

Data Sources	Inclusion Criteria	Justification
Patient Participants who:	• had a stroke,	Patients with stroke have unique needs and goal-setting for rehabilitation following stroke is routinely done in practice.
	• were medically stable,	Care for acutely ill patients will focus on regaining medical stability rather than rehabilitation and such ill patients are unable to participate in research processes. Moreover, it will be unethical to recruit them for a study which does not directly benefit their condition.
	• were able to communicate at an understandable level,	Patients should be able to communicate so that they can contribute to the interviews. However, patients who had mild speech difficulties were still included so that the speech and language therapist's perspectives in relation to such patients' goals can be studied.
	• were cognitively intact,	Patients should be able to understand the interview questions and contribute to the process of goal-setting and research.
	• were willing to participate	Consent to participate in research is an ethical requirement.
Staff participants who:	• must have a significant engagement with a patient	Unless the patient has had some problem which a particular professional has catered to and interacted with them about, the staff cannot discuss a

	participant	particular patient participant's needs or goals.
	• willingness to participate	Consent to participation is an ethical requirement for this study. No managerial pressure was exerted on staff to get involved in research since coerced participants will not contribute openly to the study.
Documents	• documents that recorded the goals for the patients' care	If the document stated, the word goal or plan for treatment it was considered to have information about goals and at least some reasoning for those goals.
Data Sources	**Exclusion Criteria**	**Justification**
Patient participants who:	• had other neurological conditions	Other neurological conditions have different manifestations and prognosis. Perceptions of patients with other neurological conditions may not be similar to patients who have had a sudden stroke.
Staff participants who:	• were visiting members of the team	Clinical psychologists and social workers visited the patients only if patients were referred to their services. They did not always participate in goal-setting meetings and were hence not approached for the study.

4.1.4 Screening, approach and recruitment of participants

All patients who were admitted during the study period were screened for inclusion in the study by the researcher who collected information about name and date of admission from the ward clerk. Potential candidates' records were screened using the inclusion and exclusion criteria. If patients were found eligible, based on the criteria, then patient participants were given information sheets about the study with print in large size fonts (size 14) by the researcher. The study was discussed at the first meeting with patients and their families if they were present. The fact that the researcher was not involved in patient-care, and data was being collected for educational and quality improvement purposes, was made clear to patients. If the patient required it, the study information was read to the patient by the researcher. After 24 hours, the researcher had a second discussion with the patients to clarify any queries about the study. If the patients were willing, either they signed the consent forms themselves or if they had arm impairments that prevented them from signing, their carers signed it on their behalf. If the patient refused participation, reasons were noted down for refusal (Tong, Sainsbury and Craig, 2007).

The staff participants were informed about both studies by the researcher during their in-service programmes. The staff who fitted the inclusion criteria were approached for participation by the researcher. They were given the staffs' version of the information sheet with study details and signed consent forms if they were willing to participate. The participant information sheets for patients and staff and consent forms for patients and staff are attached (appendices 4.2 a, b, 4.3 a and b).

4.1.5 Data collection

Different methods of data collection that were best suited to meet the objectives were employed. Moreover, triangulation of data collected using different methods and from different sources was done to corroborate or explain findings thereby improving trustworthiness of data. To illustrate the role of the different methods in collecting relevant data and how they complemented each other to achieve the purposes of this study, they are laid out in the table 4.2 below.

Table 4.2: Role of different methods used for data collection

Method	Purposes	Application	Advantages	Limitations
Semi-structured Interviewing	To understand meanings constructed by participants regarding the goal-setting process. For example, to explore the perspectives of the participants on the issues, the patients' contribution and the professionals' role in the process.	Interviews were done by researcher face-to-face. Separate question guides[3], for the patient and the professional were designed based on relevant literature to standardise and to create logical flow in questioning (Lawler *et al.*, 1999; Wressle *et al.*, 2002; Cott, 2004; Holliday, Ballinger and Playford, 2007) (Patton, 2002 p.343). Questions looked at patient needs, goals, motivations, barriers and strategies for the application of patient centred goal-setting (appendix 4.4).	Researcher was able to explain terms and probe responses to collect relevant and in depth data (Robson, 2002, p 276). Question guides helped to focus on the topic rather than having non structured interviews producing data unrelated to the focus. Personal opinions and views were collected without social desirability bias.	The space on the ward for patients who could not get away from bed was limited in privacy and was noisy. Interviews on ward were interrupted by staff carrying out their routine duties.

[3] The question guides were formulated based on the literature. However terminology was simplified with the input of the supervising team and modified to explore goals implicitly to avoid socially desirable responses from professionals. Questions were further refined based on a pilot for a previous study by the researcher and adapted for the current study relevant to the evolved research questions.

		The interviews were conducted in the meeting rooms or on the bedside. Digital recorders were used for recording for later analysis.		
Non-Participant Observation	To understand the context of decision making regarding goals for rehabilitation, the work culture, the spatial arrangements, interaction, team dynamics and behaviour of professionals during goal discussion with the patient participants (Mulhall, 2003).	Unobtrusive non-participant observation of the goal discussion meetings (weekly case conferences and ward-rounds)(Gibbon, 1999) were done. The observations were overt for ethical reasons, that is, the team members were informed about the research purpose and the researcher's presence in the weekly meetings. The behaviours of team members or participants immediately before or after these meetings were also observed. The observations were written down as field notes (Mays and Pope, 1995).	The authenticity or the possibilities of socially desirable responses from the participants during interviews were cross-checked using observational data (triangulation). Behaviours, moods, different aspects of professional roles, aspects that were forgotten or not revealed in interviews were identified (Mays and Pope, 1995).	Observations were found to be influenced by selective attention to data since they were non-structured.

Document Analysis	To capture the decisions made regarding goals and the priorities of the healthcare professionals (Bendz, 2003). To examine the written form of communication between professionals regarding patient care and goals. To study the voices of the patients within these documents.	Notes were made from the goal-setting documents that were a part of the patient's medical notes. This work was done on-site as removal of records from ward and photocopying of these documents was legally prohibited. The data from the various documents was summarised in a generic table format for standardised data extraction for further analysis (appendix 4.5).	Documents provided actual record and timeline of decisions made and communications within team and to patient (Yin, 2003, p. 85). Records were not influenced by reactive bias due to intrusion or influence of researcher (Bowen, 2009). Records were readily available on the wards and were analysed at a time convenient to the researcher. Data from other sources were corroborated using the data from notes (triangulation).	Documents were not completed in certain cases. Multiple documents and voluminous notes had to be screened which was time-consuming.
Focus groups	To explore barriers and facilitators for patient-centred goal-setting from the perspectives of patients and	Staff from the different professions involved in goal-setting participated in the focus	Focus groups caused interaction amongst patients who were otherwise isolated	Joint focus groups with patients and staff were considered, but were not conducted due to the power differences between

	professionals. To get their collaborative views on how to improve the process.	groups. The question guide[4] for this study had questions relevant to understanding concepts of patient-centredness and goal-setting and operationalising these concepts (appendix 4.6). The researcher facilitated the patient focus groups while the clinician involved in the research facilitated the staff focus groups so that authority did not influence views of patient participants.	and bored on the wards. Peer support was observed amongst patients during patient focus groups. Valuable data from multiple patients and professionals was collected within a short period of time compared to interviews. Ideas from staff were influenced, challenged, refined by others' contribution, unlike an individual's personal perspectives collected from interviews (Robinson, 1999).	the two groups which could inhibit patients from expressing their opinions in the presence of staff. Though four to eight participants is considered as an optimal group size (Kitzinger, 1995) practical limitations such as quick patient turn over and continual engagement of patients in diagnostics in acute stage limited patient numbers in each group.

[4]. Questions to guide discussions in focus groups were set up based on literature and to meet the aim of the research (Ruff, Alexander, & McKie,2005)

4.1.6 Data analysis

Analysis of data involved an integration of approaches including sequential analysis (Miles and Huberman, 1994, p.85-89) and the case study analysis (Yin ,2003), with methods adapted as appropriate to answer the research questions. For example, the key question about what aspects of PCGS were adopted in practice, required methods that could specifically analyse the presence of patient-centred components within data. A straightforward derivation of themes using a simple thematic analysis would not have made this evident. Therefore a framework method was considered to analyse data, in which the components can be used as a-priori themes to identify which aspects of patient-centredness were used in practice (Ritchie and Spencer, 1994, p 173-194). This was carried out up until a certain stage when it became clear that the steps in framework analytical process were identical with those of strategies in sequential analysis and use of matrices described by Miles and Huberman (1994). What follows is therefore, for the sake of simplicity, discussed in terms of sequential analysis set out in the steps of "(1) Data reduction, (2) Data display, and (3) Conclusion drawing" (Miles and Huberman, 1994, p. 10) in the following subsections. Sequential analysis was followed by intra-case analysis to draw inferences from across the multiple cases which is described in section 4.6.1.4.

4.1.6.1 Preparation of data for analysis

The data from the entire set of interviews and focus groups involving staff were transcribed verbatim by professionals from transcription services. Though transcription by the researcher would have improved immersion in the data, time was limited. However, researcher bias in misinterpreting words during transcription was avoided. The transcripts were checked for accuracy by the researcher while listening to the recordings simultaneously (Easton,

McComish and Greenberg, 2000). The patient interviews and focus groups were transcribed by the researcher considering the personal information revealed, and slight speech difficulties in some patients. This process also helped the researcher to engage better with data. The field notes were typed up. The data were then set out in the Microsoft Word (2010) program for analysis.

Though Qualitative Data Analysis Software (QDAS) have been recommended for their thorough and efficient reduction and management of data leading to a rigorous analysis and visible audit trail (John and Johnson, 2000), in this case the researcher as a learner perceived better engagement with data while using manual methods. The researcher found analysis using software to be over engaging, with coding potentially distracting the analytical process of 'making meaning' of the data (Dohan and Sánchez-Jankowski, 1998). In addition, despite the advantages of QDAS, the retrieval of coded data chunks stripped the data of the context; the researcher could not rekindle the emotions associated with the data from memory (Sandelowski, 1995), for example, there was at times a degree of sarcasm not evident from words but from recollection of expressions during interview.

4.1.6.2 Data reduction

As a first step the researcher listened to the audio recordings and reread the transcripts to become familiarised with the data (data immersion). Meaningful segments of data were assigned codes that were initially descriptive. During repeated and revised coding, these codes were more interpretative as the researcher gained more understanding of the motives operating in the research context (Miles and Huberman, 1994, p 57). These codes were not purely inductive, as the researcher was familiar with the theory in this area. The researcher was constantly going back and forth within one transcript or between transcripts and

constantly refining codes to ensure the codes corresponded to conceptually similar data, specific to the segment and were not too abstract. Then the next step was to develop categories that were broader concepts that pulled together one or more of these codes. These broader categories, or pattern codes as Miles and Huberman refer to, reflect the theory (largely influenced by the systematic review), aspects of research objectives and were at a higher level of abstraction than the open codes (Miles and Huberman, 1994, p 58). The categories and the codes that corresponded to these categories were colour coded for easier visual scanning of data based on the colours. Mental notes, doubts and reflections about issues which the researcher considered important for later perusal were typed up within double parentheses. Sample of coded data has been provided as appendix 4.7. A second analyst independently coded two interview transcripts for this study; her thoughts about the data were considered carefully during interpretation of the study.

Following the coding of interviews and field notes, spider diagrams (cognitive maps) were drawn up for the first study to link the codes, visually display the relationships between the various categories and gain understanding of each case. These were written up descriptively as case summaries keeping as close to the original data as possible. Analytical memos were made when these descriptive summaries were made (table 4.3). These case summaries for each case helped to synthesise, condense the data for better management for further inter-case and intra-case analysis at a later stage.

Table 4.3. Extracts from a case summary along with memos from Study one

CASE SUMMARY: Maggie (40 yr old lady) was a trained afro-Caribbean nurse who worked as a carer. She was a single mom with three kids. Prior to her stroke she was doing a carer job, did most of the household chores and helped the people who she cared for….The onset of stroke was sudden and hence a shock for her. However she was aware that she was having a stroke straight away and more so when the medics told her at admission. This was possibly because that her mother had had a stroke at around her same age, she along with her other sisters had high BP and had been stressed around the time that she had a stroke. She realises that all of this could have contributed to her stroke. Her fears at onset were about whether she was going to get worse, whether she will recover. At worst she feared that she would die like her mother did after a year of stroke at 41. So at the stage she wanted psychological support and texted all her family and friends about how she felt and they reassured her that she would be fine as she was a strong and positive person. Her family's support and encouragement seemed to help her cope with the suddenness and shock. She also believes that her mental strength has helped her cope. …. brought back worst memories of her mother's stroke (vicarious experience)…She also feared that she might have a second stroke that would make things worse….With regard to her goal setting she perceived that goals were for people who were younger. When explained the concept of setting goals for her rehabilitation in the hospital she said was determined to get back to her previous status. Therefore she was sure of her goals. She had not been asked for her goals. But that did not matter much to her for various reasons. She was fearful of discussing issues in her care for fear of being branded as an awkward patient. She was not sure whom to talk to. She did not trust everyone on the ward. Furthermore no one had asked to involve in setting her goals. If all these professional issues were sorted out she would seek guidance in decision making if she needed it. She perceived that staff would think asking questions would be interfering in their job. She would appreciate advice from health professionals since she did not have recent experience in the hospital. But she was not totally inclined to fit in to a system and get involved as she was self-determined to set and follow up her goals on her own.

MY THOUGHTS:

- ((Patient's health beliefs were highly influenced by her family history of stroke. Her impressions about the healthcare were influenced by her family's and her

previous experiences.

- She seemed highly motivated with setting her own goals. However her negative impressions about healthcare professionals' attitudes were major factors that stopped her from getting involved. So this barrier arising from previous experiences must be screened for early on before seeking involvement.
- Even as a patient who is self-motivated, cautious (assess risks), problem solves and prioritises recovery; she seems to have the fears that are common- second stroke and recovery doubts. Their primary need is reassurance and help with coping- more of psychological needs.
- She is yet another patient who thinks it should be left to the person whether they get involved or not. ANDREW had felt that not all of them could take all of the information.

With regard to analysis of documents the information from the different documents was summarised in tables (appendix 4.8) with relevant details about professionals who completed them, the event recorded, details of event, professionals' plan of action and rehabilitation goals (Appleton and Cowley, 1997). This summarised data was inputted for the next stage of analysis. Though the document data in this summarised format was useful for triangulation purposes, the analysis was considered selective rather than comprehensive.

4.1.6.3 Data display

Display of data from different sources within each case was done in two ways to answer different questions. For the first question about whether practice was patient-centred and if so which aspects were adopted, conceptually clustered matrices were set-up in Microsoft excel spread sheets (Miles and Huberman, 1994,p 127; Rosewilliam *et al.*, 2015) (appendix 4.9). The components of each of the dimensions of patient-centredness were set out as *a priori* labels. Chunks of data from each case summary were inputted under these *a priori* labels in four rows pertaining to patient views, professional's views, observations (field notes) and documents. The inputting of data chunks from case summaries required understanding of the definitions and boundaries of the components and ability to relate the meaning of the

summarised data to the components of patient-centredness. In some situations, certain chunks of data were suitable to be classified under more than one component. The researcher's interpretations along the course were inputted in a spread sheet for iterative analysis. These interpretations corresponded to similarities, differences, deviant cases, possible explanation, further questions, and sometimes related to external theory.

The next step in data display was to screen the spread sheet to identify to what extent any particular aspect (component) was adopted in a specific case. It was decided that if an aspect was identified by a patient, and a professional was aware of the issue in this aspect and other sources like meeting discussions or notes confirmed this, then this indicated congruence between the sources of data (Triangulation). Reasonable assumptions were made to infer that levels of congruence in evidence from the different sources of data, indicated levels of adoption of a component in that case. This gave rise to a continuum from being reasonably good congruence at one end to not being so at the other. The different levels were classified based on patterns of congruence as described below.

Pattern 1: Reasonably good congruence – when aspects of a particular component were evidenced within patient's data and was corroborated by more than one other source of data and at least some goals were set relevant to the identified needs.

Pattern 2: Partially congruent – when aspects of a particular component were evidenced in two sources of data showing some awareness of this component.

Pattern 3: Incongruent – when the component was evidenced in a patient's data but other sources were contradictory or lacking, or when relevant goals were not in place for a

particular component, it was considered that there was incongruence between the patient and the system.

Pattern 4: Irrelevant – when the component was not evidenced in any of the data sources it was considered that the component might be irrelevant to this particular practice.

It is important to note that, since congruence between different sources was the key indicator, data from focus groups which could not be corroborated by other sources were not included in this display. Only data from case studies were used to understand the extent of adoption of patient-centredness.

Based on the above classification of levels of congruence, data from each of the case-studies in the excel spread-sheets were further analysed and summarised under individual dimensions in separate table (appendix 4.10). These display tables were helpful to explain reasons for varying extent of patient-centredness in cross-case synthesis in the next stage (Yin, 2003, p 156-160).

4.1.6.4 Intra-case analysis

The next step was a strategy to gain an overview of extent of adoption across cases and indicate the overall levels of adoption of patient-centredness in this setting. The case numbers were clustered in a table under different levels of congruence for the different components of each dimension (appendix 4.11). The clustering or spread of cases across the continuum of different levels of congruence indicated the extent to which a particular component was adopted in the practice setting.

In order to answer the other questions regarding factors influencing extent of adoption of patient-centredness, additional tables were used to display data from the case case-studies and focus groups (Miles and Huberman, 1994, p 93). Expanded codes (to make meaning to analyst) from each case and focus group were tabulated against the main categories derived during the analysis. Three tables were set out pertaining to the questions and the participants (patients and professionals). Parts of these tables are provided in appendices 4.12 a, b and c). These tables helped to analyse multiple features across cases by examining similarities and differences (Yin, 2003 pp 156-160) and derive interpretations and conclusive themes by using strategies discussed below.

4.1.6.5 Drawing conclusions

Following data display, the researcher derived meaning from the data in the above tables by using strategies described by Miles, Huberman and Saldana (2014, pp 275-293). Some of these strategies were used to draw data together, explain findings using constructs, identify relations between these constructs and arrive at conclusions that will answer the research questions. The various strategies are described below in table 4.4 with illustrations from study data. A sample of these illustrations of the logical process of how the researcher arrived at these conclusions (themes and subthemes) have been presented for an audit trail (appendix 4.13). These conclusions are presented as straightforward answers to research questions and as themes and subthemes in the results section 4.2.

Table 4.4. Strategies to derive conclusions with illustrations from data (based on Miles, Huberman and Saldana, 2014)

Strategy number	Strategy		Illustrative examples from data tables
1.	Noting patterns	The recurring phenomenon amongst the categories and processes; looking for similarities and differences.	For example in appendix 4.10 under the dimensions 'Bio-psychosocial', a pattern was observed that biological needs were identified by this patient, professionals and were discussed and recorded This was repeatedly seen in many cases. Hence this particular aspect of looking at biological needs was considered as showing good adoption (section 4.2.2, category 1).
2.	Making comparisons and contrasts	Comparing between roles or processes	In appendix 4.12 c the principles and strategies described by patients and professionals were compared and contrasted and identified that patients were discussing strategies towards building relationships and professional strategies were focused on modifying structures (section 4.2.4-theme 2.)
3.	Clustering	Categorising, organising events, acts and processes to group them and conceptualise.	Limitations in knowledge expressed by patients (appendix 4.12 b) were listed but were identified to fit into two types – about their condition and about the context. It was conceptualised that both of these limitations could lead to a disempowered patient stopping them from participating in goal-setting (section 4.2.3-theme 1)

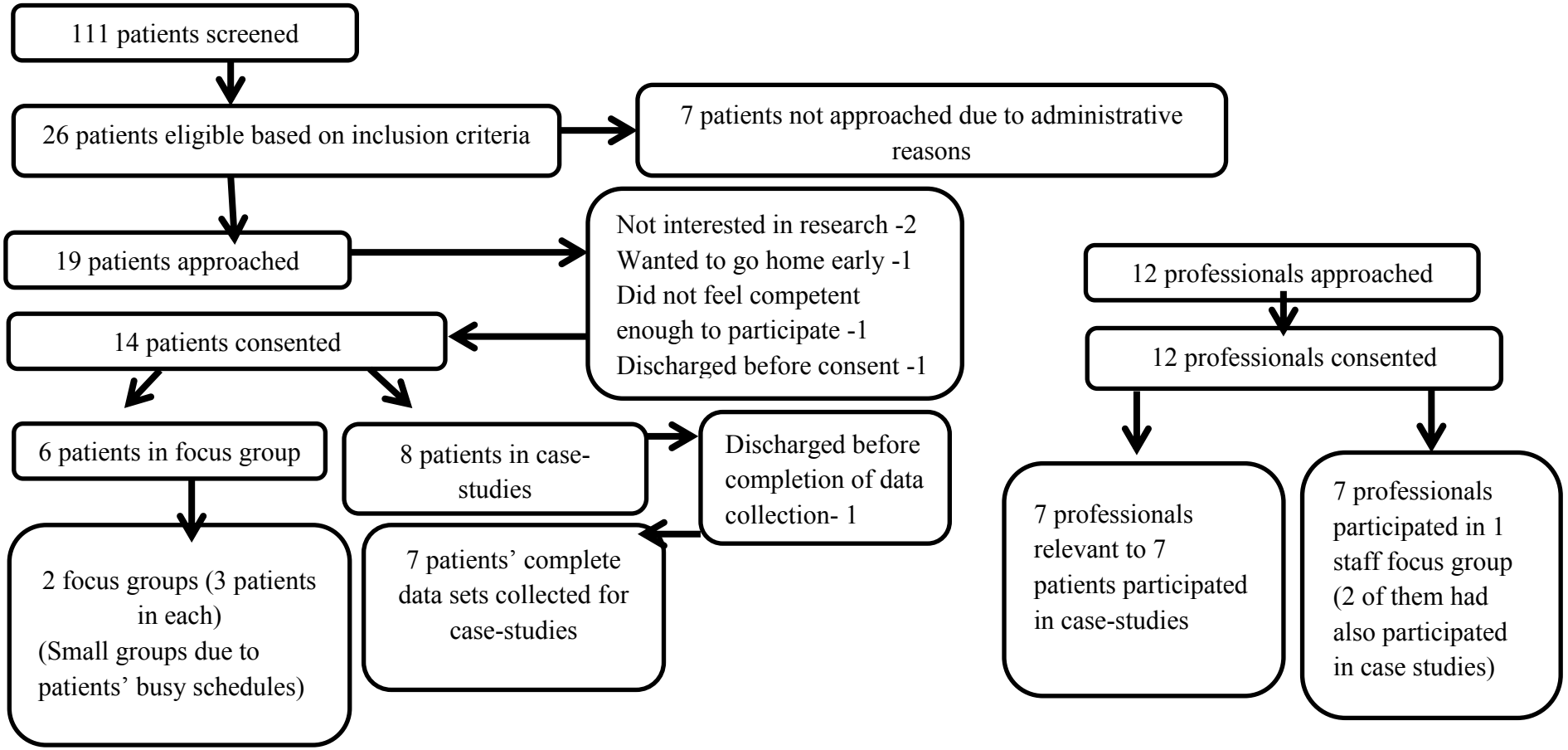
4.	Making metaphors	To abstract based on inference; see new theoretical possibilities; making a singularity of several particulars.	It was observed within data that professionals understood patients based on their profession-specific assessments, planned for treatment, set goals and gave interventions based on this (appendix 4.12 a). There was a failure to notice the bigger picture and so the metaphor ‘tunnel vision’ which implies narrowed focus was used (section 4.2.3-theme 1-subtheme 3).
5.	Counting	Rather than counting exact numbers, consistency judgements based on more often was used; show general drift of data by looking at distributions.	To answer the question whether practice had improved in adoption of components of patient-centredness (section 4.2.2) judgements were made from the display related to the distribution of cases against the levels of congruence (appendix 4.11).
6.	Building a logical chain of evidence	Factors emphasised by several participants are put together; indicate a causal link; build a chain using enumerative induction and eliminative induction.	Patients and professionals pointed to disempowered staff; hierarchy, bureaucracy and workload were considered as contributing to this disempowerment. Multiple roles for a person usually considered as enabling leadership was distracting professionals from their focus (section 4.2.3-theme 1-subtheme 4).

4.2 Results

4.2.1 Results of recruitment and data collection process

The flow of participants in the recruitment process has been illustrated in figure 4.1. The characteristics of patients, professionals, meetings and documents included in case-studies are summarised in table 4.5. The characteristics of patients and professionals who participated in the focus groups are in table 4.6. Following this, the findings from this study regarding the extent of adoption of PCGS in local practice are presented under the section 4.2.2. The findings relevant to factors influencing PCGS and strategies to improve practice have been presented under themes (1 and 2) and subthemes. Where appropriate, raw data and the data sources used to derive conclusions are presented.

Figure 4.1: Flow diagram showing the results of recruitment and flow of participants in Study one.



The seven patient interviews lasted between 24 and 51 minutes, the seven professional interviews lasted between 17 and 45 minutes. The single professionals' focus group lasted for 53 minutes, and the two patient focus groups lasted for 33 minutes and 39 minutes respectively.

Overall there were 10 types of documents that included plans or goals for rehabilitation, four relevant to physiotherapy, three to occupational therapy, one used by all professionals, one was a meeting record and one was a transfer document. However, the numbers and types of documents from these various types used for each patient were found to be variable (see table 4.5). The generic characteristics of the documents including the authorship, position, structure and content, frequency of use, and relevance to goal-setting of the various types of documents analysed has been presented in appendix 4.14.

Ten ward-rounds were observed in which a variety of professionals from the team went to speak to the patient as a group. Most often the doctors were accompanied by the physiotherapy consultant and a nursing ward manager or stroke coordinator. Nurses did not participate in the ward-rounds and occupational therapists were present in two. Eight multi-disciplinary team meetings were observed overall within the case studies. Professionals representing physiotherapy, occupational therapy, speech and language therapy, medicine, nursing manager, stroke coordinator, consultant physician, a social worker and students who were on placement on the ward attended these meetings. Nurses were represented by the nursing manager or the stroke coordinator who was also a nurse.

Table 4.5. Characteristics of included patients, corresponding professionals, meetings and goal-setting documents within case-studies

Pseudonyms of patients	**Diagnosis**	**Age**	**Ethnicity & Gender**	**Occupational status**	**Social Status**	**Length of stay**	**Professional interviewed (Keyworker)**	**Grade**	**MDT meeting**	**Ward-rounds**	**Therapy & MDT records**	**Continuation sheets**
Peter	Right ischaemic stroke	54	White Male	Software Engineer	Lives with wife	14 days	Staff 1 Occupational therapist (OT) 1	Band 6	1	1	7	As many as required
Andrew	Right Middle Cerebral Artery stroke	66	White Male	Engineer (part time)	Lives with wife	4 days	Staff 2 Physiotherapist (PT) 1	Band 7	1	1	1	As many as required
Maggie	Functional stroke	42	Afro-Caribbean Female	Carer	Single mother	4 days	Staff 3 Staff nurse (SN)	Band 6	1	1	5	As many as required

James	Right fronto-parietal infarct	84	White Male	Retired	Lives alone	17 days	Staff 4 Physiotherapist (PT) 2	Band 6	1	2	8	As many as required
John	Cerebellar infarct	71	White Male	Retired	Lives alone	34 days	Staff 5 Speech and language therapist (SLT)	Band 6	2	2	10	As many as required
Ibrahim	Right Basal Ganglia bleed	62	Asian Male	Independent social services	Lives with wife	21 days	Staff 6 Senior house officer (SHO)		2	2	8	As many as required
Mary	Right frontal haematoma Occipital infarct	70	White Female	Ward administrator (part time)	Lives with husband	30 days	Staff 7 Stroke Coordinator nurse (SCN)	Band 6	-	1	8	As many as required

Table 4.6 Characteristics of patients and professionals included within Focus Groups

Professional participants in staff focus group (SFG)			**Patient participants in patient focus groups (FG1 and FG2)**						
Staff Id.	**Professional**	**Grade**		**Patient Pseudonyms**	**Diagnosis**	**Age**	**Gender**	**Social status**	**Length of Stay**
SHO.	Senior House Officer	-	FG1-	Denzel	Rt PCA ischaemic stroke	62	M	Lives with wife	7 days
SN.	Staff Nurse	Band 6	FG1-	Katherine	?Stroke	51	F	-	3 days
OT.	Occupational Therapist	Band 7	FG1-	Christina	Ischaemic stroke	60	F	Lives with husband	9 days
SCN.	Stroke Coordinator Nurse	Band 6	FG2-	Keene	Rt MCA infarct	59	M	Lives with wife and son	20 days
SPC.	Stroke Physio Consultant	Band 7	FG2-	Harry	Lt thalamic infarct	64	M	Lives with wife	6 days
PT.	Physiotherapist	Band 6	FG2-	Melvin	Stroke	70	M	-	4 days
SLT.	Speech and Language Therapist	Band 6							

4.2.2 Extent of adoption of patient-centredness in local practice

The various components of patient-centredness (given within quotation marks below) outlined under the dimensions of patient-centredness from the conceptual analysis (appendix 3.1) were observed to be adopted to different levels in this study setting and are discussed below. Based on the distribution of cases within the continuum of levels of congruence, the extent of adoption was then classified into three categories: 1) a reasonably good extent, 2) moderate extent and 3) least adoption. 'Reasonably good extent of adoption' was assumed when the majority of cases had shown reasonably good congruence in any particular component 'moderate extent of adoption' was assumed when the majority of cases had shown partial congruence and 'least adoption' when the majority of cases had shown incongruence. The components that were considered 'irrelevant' to this setting, based on findings from this study, have been discussed in Chapter 6 after comparing their relevance within Study two.

Category 1: Components observed to be adopted to a reasonably good extent

Only two components were observed to be followed to a reasonably good extent in this study setting. Firstly, the 'biological component', which involved looking at medical, physical and functional status and relevant investigations, was seen to be adopted to a good level. Patients highlighted obvious physical issues within the biological component in all the cases. Simultaneously, these aspects were explored and goals were set, by all professionals perhaps due to their biomedical orientation. Hence the process tended to align within a bio-medical model.

> *We use the disability handicap impairments for a problem list which will identify what the impairment level is and what is it they are struggling to do.*

That may well be the direction we go in terms of what goals we set.-Andrew's PT1's Interview.

Secondly, all patient participants were 'sensitive to time and context' and thus voiced goals relevant to their roles at home, in the community or at work.

I want to get back to work. ...My work is very cognitive - I think the word is cognitive doing numbers and things like that –Peter's Interview.

Likewise professionals' awareness of the patients' needs over time and in different contexts was represented in plans for discharge, referrals for community rehabilitation and follow up. These were recorded in the notes and were sometimes conveyed to, rather than constructed with, the patients.

His goal is that he wants to get back to work… he does a lot of work around data analysis, he is functioning at quite a high executive level…-Peter's OT's Interview.

Patient was told that he will be going home if the medications arrived. He was told that plans are in place for follow up.-Field notes from Andrew's WR.

Category 2: Components observed to be adopted to a moderate extent

Certain components revealed to be adopted to a moderate extent in this study setting are described here, along with the gaps in practice and reasons why they were considered to be partially adopted, in this category.

Professionals had an understanding, in most cases, of the patient's previous medical history, marital status and job, and 'social aspects' such as whether they lived alone or with family and whether they drove. Simultaneously patients often prioritised goals around independence in activities of daily living and return to work and driving. These components mapped onto the 'patient biography' component of patient-centredness.

> *History: mother died of stroke at 41 yrs.-Maggie's physiotherapy notes*
>
> *Social: lives with 3 children/works as a full time carer for cousin/patient drives -Maggie's OT assessment.*
>
> *Participation: reduced ability to carry out ADL.-John's PT assessment.*

This partial awareness of patients' biographies was due to the mandatory need for professionals to collect demographic data and medical histories as part their of routine stroke assessments. The adoption is only partial because there was the scope for recording leisure and spirituality in professionals' assessment forms, yet these components were not evident in professional data sources. It is possible that patients raised 'leisure activity', socialising through hobbies, shopping and spirituality only during interviews, but not during interactions with professionals in ward-rounds since these rounds were brief and formal. Whatever the reason, not knowing patients' leisure activity deprived certain patients while in hospital.

> *But what I would like is the use of a radio….to plug in… how do I get a radio head-set?…-John's Interview.*

In most cases professionals had some awareness of patients' 'emotions' relevant to their 'psychological status' (which further included cognition). These were either discussed in

meetings or recorded in notes. While patients reported fear, shock, loss of confidence and control, anxiety, coping issues and frustration, staff picked up shock, anxiety, panic, reduced confidence and low mood in patients. Additionally staff also reported anger, boredom and happiness, not words which were used by patients. Yet, professionals did not monitor the areas covered by these words, nor set relevant goals for any of the psychological issues described above.

> *It's difficult to come to terms with it isn't it? You've got no control…-Peter's Interview.*

> *For him, it was quite profound because it affected his confidence, affected his balance, and it was a shock… (and on questioning about intervention)… it was mainly mobility, upper limb function, and discharge planning.-Andrew's PT1's Interview.*

Likewise, though professionals had a good 'sensitivity to different contexts', consideration of 'transition to community' was generally inadequate, especially in cases where the patient had communication or medical problems. Professionals' communication regarding care beyond the context of hospital was limited, despite patients being concerned about continuity of care in the community.

> *I think they could have told me more. Even my wife said what happens if you leave on Monday? … I said I don't know.-Andrew's Interview*

With regard to 'Health promotion' a key aspect of transition to community, patients wanted information on management of risk factors, prevention of stroke in future and current

management so as to plan for their future life. Simultaneously, professionals were keen on setting goals for the prevention of further stroke using medications.

> *Patient questioned doctor about why it had happened in the first place and whether it will happen again. He wanted to know whether it was related to his recent CABG. -Field notes from Andrew's WR.*

> *For patients having irregular heart rate, starting warfarin to prevent a further cardio-embolic stroke…We explain to the patient…giving him some leaflets and information about stroke… also we have a gentleman who is our stroke association person. –Ibrahim's SHO's Interview.*

Though professionals suggested that they had delegated the responsibility of discussing health promotion to volunteers from the Stroke Association, there was no documentation of what health promotional material was delivered to these patients.

This further pointed to limited 'informational control' or the ability to gain information by the patient. Patients perceived a lack of awareness of facilities, routines, processes, their condition and goals resulting in a fear of unknown.

> *They put a cannula in when I came here first. They never took any bloods. I thought why you put in first….It's the unknown that frightens us all to death…don't know what's going to happen…-Andrew's Interview.*

Nevertheless, patients used the opportunity to interact with different professionals and gain information in most cases during the ward-rounds or used families as communication channels between the team and themselves.

Patient said his speech was affected as well. Doctor said it was expected with this type of stroke- both his speech and swallow would be affected.-Field notes from John's WR.

Discussion with husband raised concerns about discharge destination…- Mary's OT record.

In addition to limited informational control, 'ongoing multi-directional information exchange' within the team was also limited. For example, the staff stated that they collected information from each other, families, meetings and notes, indicating a good flow of information within the team, yet, it was observed that in certain cases information was overlooked leading to wasted effort or ineffective planning.

On 2/9/11- Doctor had written 'Told husband waiting for INRU from rehab hospital X. Husband said hospital Y have accepted Mary.'
And on 5/9/11 Neuro rehab consultant from hospital X recorded 'Assessed. Happy to take to Mary to X'

Ward-rounds, a key forum for information exchange, were ineffective since goals were rarely discussed, meetings were brief (7-10 minutes), and there was inadequate representation from the different disciplines. Moreover ward-rounds were usually medically oriented resulting in clarification of medical issues.

Three doctors and PT were present (SLT was absent despite swallow and speech being patient's main issue).-Field notes from John's WR.

‘Patient’s autonomy’ was a component that considered patient’s independence and provided information about activities and interventions for independence. In a majority of cases therapists had set goals for patients relevant to gaining independence in activities of daily living, self-care, mobility and functional ability. Likewise, patients had voiced independence goals in the above areas: however, they did not perceive that they got sufficient information, perhaps through their treatment plans. This may have hindered an aspiration to autonomy.

> *It was very important for her to become independent again. She always said, If I was more independent… So, that was her big goal. –Mary’s SCN’s Interview*

> *Interviewer: so do you know what your current goals for rehabilitation are? Ibrahim: nothing. Nobody has talked to me about care plan. –Ibrahim’s Interview.*

With regard to ‘decisional autonomy’ or the patient’s ability to make appropriate decisions, consultants were observed to facilitate this aspect by discussions during ward-rounds. There was also a consenting procedure in the care delivery process that required professionals to share decision making with patients.

> *This treatment plan has been fully discussed and agreed with the patient. This includes options for treatment and amendments to the plan and options for non-treatment. -Physiotherapy treatment record.*

Despite these opportunities to share decision making, patients’ choices were sometimes overruled by professional plans – though patients could successfully resist this on occasion, it appears:

On 24/8 PEG referral sent but person on leave- to send to another person…

On 30/8 Patient refusing PEG… -John's continuation sheets.

With regard to 'active participation', most patients did not perceive they were involved in goal-setting. This was probably because some professionals stated that the goals were set in MDT meetings where the patient was absent and others suggested that they had discussed goals with the patient outside the meeting but used simpler words. This may have made the goal-setting process implicit, rather than transparent and visible.

It's usually with the team. All the team is sitting down weekly, the MDT, discussing each patient separately. –Ibrahim's SHO's Interview.

As a result of partial adoption of the above components, 'personal relevance of goals' according to which goals were relevant to daily life, and 'congruence in goals', when patients understood common goals and agreed with them, were limited in practice. Therapy records had a section for patient-agreed goals which was left incomplete in most records. However, as discussed in category one, personally relevant goals were possible when patients voiced goals which were bio-medically oriented and within the professional remit. Personally relevant goals also seemed to be established when families acted as communication channels.

To try and get his muscles working again… trying to get him to do something for his arm and his leg, and then looking at sitting balance…-James' PT2's Interview.

Told husband (they were) waiting for INRU from M (discharge destination). Husband said W (patient preferred destination) had accepted patient –record of Mary's ward-rounds taken from her continuation sheets.

Finally, most patients and professionals considered 'Carer and family involvement' important; yet, clinicians had reservations regarding family involvement in case the families were argumentative, or overprotective. Also professionals were conscious of their own busy schedules.

We have no time to sit down with the family, to find out. The family are the best people to tell you more information… We have been told by staff nurse that the patient is going to have this…they start arguing. –Maggie's SN's interview.

Category 3: Least adopted components

The 'psychological world' of the patient (defined in the conceptual framework as involving motivations, values, and preferences) that drives the patients' goals was not explored in most cases. Patients expressed motives such as enjoyment, a sense of achievement, a need for peace, for relaxation, socialisation, caring for others, companionship, a sense of control and autonomy.

Some control and also know what's going on….Everything is being done for me. If you did everything for one's self….I will be more aware won't I? – Ibrahim's interview.

The ‘patient’s subjective experience of illness’ (how patients perceived their illness and hospitalisation) seemed to influence their identification of limitations and relevant goals.

> *I’ve been doing series of tests yesterday which highlighted to myself the difficulty of doing things … Because I play the guitar for a long time I want to see if I’ve still got the ability to do that... -Peter’s Interview.*

However, professionals often stopped at describing the attributes or behaviour of a patient such as being ‘chatty, demanding, argumentative, weird, non-compliant, angry, and confused’ (from different observations and staff interviews). They did not generally appear to demonstrate an understanding of patients’ motives which underpinned these behaviours. An exception was in Mary’s case. Mary was working as a ward administrator in a different hospital when she had her stroke. Her keyworker identified that patient was embarrassed to be rehabilitated by her colleagues; this led to a modification of her discharge goal

> *…because of the fact that she used to work there, and she knew people there, and she didn’t want people to see her at that stage, which we thought was reasonable. Mary’s SCN’s Interview*

This was a case different to the others where the system was flexed to accommodate her specific needs.

The negative perceptions of their patients expressed by some members of staff (e.g. a patient was “demanding”), might at worst have been sensed by patients in some cases which would hardly help in the development of trust, or a proper therapeutic relationship generally. Dissatisfaction with care and anger were also observed offering further evidence of a dysfunctional therapeutic relationship.

The patient was up and about all the time, as you could see. She was arguing. She was telling you this one minute, telling you that one minute, arguing about another thing… One minute she was confused… -Maggie's SN's Interview.

It depends if I trust you…not everyone…because not everyone is trust worthy, whether they are in the health profession or not. –Maggie's Interview.

To be honest with you this is one of the worst establishments that I have been to simply because they don't listen.-Ibrahim's Interview.

'Self-efficacy beliefs' were discussed by most patients related to their beliefs about recovery, time for recovery and their life-style prior to stroke. Contrarily, this was not facilitated or mentioned by professionals except when they discussed patients' lack of confidence.

Fortunately my physical side hasn't been affected. I feel like I could continue. It's a lot of do it yourself. You feel like you have the ability I think it's sort of something like instinct isn't it? -Peter's Interview.

Overall, considering 'Patient as an expert' was not observed except in two cases. Rarely, patients were given opportunities to identify problems or their issues acknowledged and their knowledge was taken advantage of. Sometimes, patients' understanding of problems was explored, problems were broken down, and possible causes and solutions explained during ward-rounds.

He said he was feeling dizzy… Doctor asked him when he felt dizzy and patient said when he was being shifted into a chair. Doctor asked him whether

he knows that he has a stroke and problems with co-ordination and so he will have a bit of a wobble. –Field notes from John's WR.

Discussed with husband who says bed is available in Wolves. Plan: to contact Wolves and request discharge forms tomorrow. –Mary's continuation sheet.

Contrarily some patients did not consider themselves as experts as they felt they did not possess the relevant knowledge; and certain professionals reflected this opinion, suggesting patients might be unrealistic, and might lack experience and insight.

But sometimes we're in a better position to know what they can achieve and what sort of length of time period. –Andrew's PT1's Interview.

As a result they sometimes said that patients set generic and unrealistic goals which they had to modify or tone down.

He was a little bit unrealistic, really, he would sometimes say, I'll be walking with my stick in a few weeks. I don't think was not really that realistic, so we had to lower the stakes. –James' PT2's Interview.

Thus, there was minimal evidence to support professionals exploring 'active problem-solving' or encouraging 'strengthening problem-solving skills' with patients. This was despite the observation that most patients showed tendencies to put forward problems, prioritise them and seek out solutions.

I can't walk. Same thing has happened to the left leg. I know it's only getting from one place to another I suppose I can do that on the chair. A propelled chair can do that to move you around.-James' Interview.

'Executional autonomy' or the ability of patients to carry out decisions or delegate actions was limited in this setting with no evidence of staff encouraging this aspect. Indeed, one patient's (Maggie's) decision to walk to the toilet on her own was frowned upon as she had been instructed not to for safety reasons. However, certain other patients on their own initiative had delegated responsibilities to families or carers to fulfil their aspirations.

> *Patient was seen coming back from toilet on her own...reported to senior staff. Maggie's nursing records*

> *I suppose to get some money out for odd things like soft drinks and paper and magazine…someone will ring… I will tell her [to fetch his card].-John's Interview.*

Components related to 'clinician's attitudes', 'professional respect', 'maintaining positive hope' and 'bonding' were observed to be adopted to a moderate to minimal extent which was again not conducive to building a therapeutic relationship. Though patients did not voice any opinions about clinicians' attitudes openly, some patients' observations suggested that they perceived clinicians' attitudes as being negative. In some cases clinician's attitudes resulting from poor communication skills were interpreted as professional disrespect.

> *She shouted at me just for this breakfast. I don't know why and how I jumped out of my sleep and I felt worse than when I went to sleep. I was so shaken and weak, it felt like a shock. –Maggie's Interview.*

> *Simply because they don't listen…They don't treat you like a human being… If you won't come and talk to me as a patient what can I do?... -Ibrahim's Interview.*

Moreover, except during ward-rounds when the doctor discussed their medical improvement or discharge plans, there were no instances of professionals giving hope or reassurance which the patients were very keen on. In fact giving information that could give positive hope to the patients was considered as a challenge by staff.

> *Well give me confidence that it is going to get better. –Andrew's Interview*

> *If you just give them information before the doctor gets to them, you have actually made a big mistake because they will quote you to the doctor…we have been told… that the patient is going to have this. –Maggie's SN's Interview.*

On the positive side, in some cases, observations revealed certain attitudes of professionals which were conducive to bonding, such as being friendly and patients reciprocated this friendliness. Consequently, where patient and clinician perceived positive attitudes in each other, there was evidence of a better working relationship.

> *Consultant sat on the bed (personal gesture). Patient sat on the chair...He asked P whether he had any questions. Doctor said it was good to see us both as he left. Field notes from Peter's WR.*

> *I think all the physical care has been fantastic and the information that the doctor has provided has been fantastic.-Peter's Interview.*

'Environmental aspects' were not considered by patients and professionals except in two cases despite this being within professional scope of OTs. It is possible that, since most

patients moved on to further rehabilitation, goals related to home modifications were left to the sub-acute team.

4.2.3 Theme 1: Challenges to PCGS

Challenges for the adoption of PCGS are described below. These were found to be related to the beliefs and attitudes of patients and staff, the culture, context and resources within the healthcare system.

Subtheme 1: Patients' reluctance to participate based on their experiences and conceptions.

There was evidence that patients' beliefs about the healthcare system and professionals had been moulded by their experiences, both from their own past, current and vicarious experiences. Vicarious experiences in some patients had enabled coping and realisation of their potential to set personally relevant goals, but in most cases had deterred participation.

> *They couldn't speak for a long time and it came back to normal. I couldn't speak but I constantly tried and it came back to normal.-Peter's Interview.*

> *You don't feel like…have I done something wrong? I was in the place and she said fasten your shirt up. She did it with some sort of aggression on her face.-Melvin in FG2.*

> *Like I said my son's aunty… I have gone through it with her for the past three years. She has got issues with the whole system let her down totally.-Maggie's Interview.*

As a result of these experiences patients believed that professionals could mock them, brand them as a bother or be hostile.

> *But this doctor unbeknown to me has munched me. He says at the end of the day it can't be that much wrong with you. -Katherine in FG1.*

> *I don't want to be a pain in the neck… ask your colleague they'll tell you. – Ibrahim's Interview.*

Moreover, patients held certain conceptions such as that goal-setting was the clinicians' responsibility, that clinicians knew patients' goals, that goal-setting was for younger people, and that collaborating with professionals restricted their freedom to pursue their own goals.

> *They probably know why, …when people come in here, they know the main wishes of the people are to walk out properly. –John's Interview.*

> *I am at the end of line now. You don't look towards the future. The future is every day. –James' Interview.*

It is possible that the patients had a mental block, resulting from their beliefs, experiences and observation of the professionals' behaviours, which led to limited participation. This mental block was assumed because some patients had discussed their goals with the researcher but not with professionals. Moreover, some patients who had shown attributes of mental strengths such as motivation, self-efficacy beliefs, determination, delegation skills, proactivity and ability to problem solve had felt inhibited to participate.

As soon as I get out of bed I walk down the corridor twice because I want to get out of here. I want to recover. I want to get back to my normal life. – Andrew's Interview.

They come across as being rushed and unapproachable. The best intentions are I can speak for myself but I come across them like that I just run …You never know what they will think when you ask them. It's all in the mind… Katherine in FG1.

Therefore, patients were seen to be content with their limited involvement or devolve decision making to doctors in view of their expertise. On the other hand, some patients set their own goals and showed determination to work towards these goals.

(On being questioned about involvement)… Not specifically…. they already know…by being professional medical workers. –John's Interview.

I don't need anyone to discuss with me because I am wary of what I am doing anyway. –Maggie's Interview.

Subtheme 2: Patient disempowerment due to deficits in communication

Patients suggested that they had limited knowledge of their condition, its severity, prognosis and their abilities, which disempowered them within the goal-setting process. Further, not knowing the professionals' roles, routines, their own roles and ward resources hindered their participation. They attributed these deficits to not getting adequate information or a lack of open communication with professionals.

If only somebody would talk to me. Bear in mind these are professionals who have seen lots and lots of stroke. They should be able to tell me what some of the barriers are that I'm going to run into.-Harry in FG2.

Overall patients considered the two way communication faulty since clinicians collected information relevant to their practice, but without listening to them; rather they gave instructions or used jargon.

When I came in they asked a lot of questions, you try to get answers to your best ability. Then you know they don't say what they think…and sometimes you are so bogged down with bits that they have told you…-Christina in FG1.

Subtheme 3: Uni-professional assessments supported the bio-medical model

Professionals came to understand the patients through their profession-specific assessments. The discussions in meetings and records showed goals relevant to the deficits identified by these assessments.

SALT felt that he had cognitive problems that are subtle. OT said there was nothing and he seemed okay with them…. -Field notes from John's MDT.

Mini MDT goals were recorded as to improve postural control, independence in washing and dressing and monitoring swallow. -James' documents.

This "tunnel vision" seemed to orient professionals to work within a bio-medical model by prioritising medical stability, safety and assessments.

Realistically we can't do that because we have got to get them medically fit and that's the main.-SN in SFG.

It seems to me this is a period of assessment, ongoing assessment which route they are going…-PT in SFG.

In contrast to this bio-medical model, patients suggested that they valued a therapeutic relationship within which professionals considered their intellectual ability, personal needs, gave them hope, reassurance, confidence and feedback on performance. Professionals, though they considered a good relationship with patients as important (*a very good person to work with- Peter's KW*), most patients' comments suggest that they seemed to work otherwise. Thus, a bio-medical approach disregarding a therapeutic relationship resulted in patients having lesser involvement in decision making.

Treat me like an intelligent person… I asked for my goals. ….we haven't come to a conclusion yet. How can you come to conclusion without involving me? – Ibrahim's Interview.

Subtheme 4: Professional disempowerment

Both professionals and patients painted a picture of disempowered professionals, who despite a motivation to be patient-centred found it impossible. Often these issues were bureaucratic and undermined the professionals' authority. The need to involve senior staff to validate decisions was seen as getting in the way, as were issues of ensuring confidentiality and minimising complaints. Sometimes these professional issues prevented information flow to patients.

So, if he is ENT consulted, then we will give him the appropriate exercises, etc. If eventually he is not to do them, then we have done our best…I think I suspected that's what the issue was, but I did not feel like I could say that to him, knowing the situation in our department…-John's SLT's Interview.

Especially with this kind of age we are in, our hands are quite tied because you don't want to get yourself into trouble for no reason. .they will start complaining that they have been told, and they mention names straight away. –Maggie's SN's Interview.

These hierarchical glitches undermined autonomy in certain groups of professionals; they did not attend the multidisciplinary meetings or the ward-rounds, did not set goals for patient care and had limited collaboration in assessment and goal-setting due to their work routines and high caseload. Even the goals discussed in the MDT meeting did not seem to cascade to these professionals.

If we got bit more staff from nursing point of view… There's too many patients to one person you know and its unrealistic…-SN in SFG

I think these decisions are made within the meeting with those present, but maybe they're not communicated… You need it cascaded with the rest of the people involved in the patient and their care. –Andrew's PT1's Interview.

Moreover, an increased workload with multiple roles on different wards and more paperwork meant more time spent away from patients. Beyond that, professionals felt ill-trained in the relevant area including in methods to implement PCGS.

It's hard for the speech therapist because we are not really based on the ward. That makes it harder as we cover the rest of the hospital as well. –SLT in SFG

We have never done any training on goal-setting have we? So we are asking our patients to understand it when we are not sure we understand it either. – SPC in SFG.

Patients were sympathetic with many of these problems (*don't walk, they pitter patter-Andrew's interview*). However, they also felt professionals occasionally lacked the necessary social skills or detailed knowledge of their particular problem for effective discussions.

I think sometimes they (staff)… are a bit worried about committing themselves in case it doesn't ring true …when they are not so sure. -Christina in FG1.

Subtheme 5: Professionals shift responsibility to patients for lack of involvement

Professionals suggested that patients' fluctuating condition, its severity, co-morbidities and insufficient cognitive ability to gain insight in to their situation, limited their communication and hence involvement in goal-setting. Professionals' knowledge of these medical aspects influenced their beliefs about patients' recovery, which in turn overshadowed the goal-setting process.

But I think it's difficult when the stroke patient has a lot of other problems as well, in terms of understanding, and they cannot always express what they want to say … -Andrew's PT1's Interview.

I think that says a lot about his cognition and insight, really,..-Ibrahim's SHO's Interview.

In some cases, professionals suggested that patients lacked psychological attributes such as motivation and interpersonal personal skills to discuss goals with the professionals. Overall professionals considered goal-setting a hard concept for patients since patients usually held a long term view of goals, set ambiguous, unrealistic or generic goals very different to their professional goals. In challenging situations, they opted to make decisions on patient's behalf, undermining the patient's expertise and patient empowerment.

> *The one that is not really bothered you're probably not going to say much for him, and that is the way it should be, because you have someone that is not motivated, they're not going to engage with the therapy… - John's SLT's Interview.*

> *Things like patients having unrealistic expectations. Because they happen to not know since they have not had them before.... -SHO in SFG.*

> *The ability to understand what we do and why we do it? And even the good old question of capacity. Some patients we treat and we think we are doing patient-centred isn't it?-OT in SFG.*

Subtheme 6: Professionals' perceptual gaps regarding their goal-setting practice

Professionals voiced certain perceptions suggesting that they were patient-centred in goal-setting. However, opposing views from patients and observed practices showed that the above perceptions of professionals might be misconstrued, evidence for which is presented below.

Some professionals believed they had involved patients in goal discussions either explicitly during therapy time, or implicitly by asking them for their preferences, or by using simpler terminology. Thus they felt they were patient-centred in the process without using those

labels. However professionals' perceptual gap about practice was highlighted by the fact that patients had not perceived this involvement and in some cases professionals agreeing that they did not involve patients.

> *I don't think there is anything in the system that stops me. I think the system encourages me to explain, listen to the patient, and involve them in goal-setting….-Ibrahim's SHO's Interview.*
> *Nobody has come forward. I'm quite willing to contribute towards it.-Ibrahim's Interview.*

Professionals perceived that goal-setting was carried out in the MDT meetings following joint assessments with other professionals and these discussions were conveyed to the patient. However observations showed that professionals discussed the patients' condition and their input without a discussion or record of goals during the meetings. Further the notion of goals being conveyed to the patients was a misperception as many patients had not been aware of their goals.

> *We do it through the MDT, really…We do lots of joint assessments on this ward, so we discuss in the teams…we say, what sort of rehab do we think this patient would benefit from? We will each give our feedback, and then plan for the rehab.-Peter's OT's Interview.*

> *PT said he is cognitively intact and PT is trying to get his sitting balance better…OT reported that they needed to assess his cognitive abilities…Sitting balance wasn't good enough and they were focusing on washing and dressing.-Field notes from James' MDT.*

Yes we will say this is what we are working towards-PT in SFG.

Subtheme 7: Contextual barriers

The challenge to setting patient-relevant goals within the hospital setting was that patients suggested they were unaware of their needs until they were in their home context. Likewise, professionals suggested that there were inadequate resources to assess their needs within the hospital setting or at the point of discharge. Furthermore, there was no privacy on the ward to discuss sensitive issues with patients.

I don't know because I haven't got out yet. I'll only know when I get out of these walls, when I walk out these doors… -James' Interview.

Obviously, the environment is limited, isn't it?… where the patient says to us, for example, I want to be able to get out on my scooter. Where would we take them to do that? -Peter's OT's Interview.

When you're talking to a patient it's not very private…You don't want to speak on sensitive issue, because that can be awkward. –James' PT2's Interview.

4.2.4 Theme 2: Principles and strategies to improve PCGS

Patients and professionals suggested patient-centred principles and strategies to implement these principles. These principles and strategies have been mapped on to the dimensions identified in the conceptual analysis to avoid theoretical reinvention and are presented below.

Subtheme 1: Individualistic approach

Patients insisted on professionals understanding their individual differences, including differences in personalities and hence their different needs. They called for tailored interventions to suit their individual needs.

> *Because yours may be different from mine and mine maybe different from someone else's...-Harry in FG2.*

Within an individualistic approach, patients suggested strategies such as to ask specific questions to explore patients' needs and pre-stroke status. One patient suggested that this information on pre-stroke status should be a reference point for setting goals. One to one contact was suggested as useful to gain understanding of a patient's needs.

> *What's your problem? What is your need? If you don't ask those questions you are not going to get an answer. –Andrew's Interview.*

> *I think you need to ask them what their previous lifestyle was because if you ask them what's your goal they would need something to relate to… -Peter's Interview*

Though professionals' favoured this approach, their strategies were oriented towards tools that helped them understand the individual characteristics of a patient.

> *It may be having a patient questionnaire that is not so structured, but they could just come and vent whatever the issue is, maybe the pressing issues, and then we could maybe use that in planning. –John's SLT's Interview.*

Subtheme 2: Patient as an expert

Patients unanimously wanted involvement in goal-setting, nevertheless to a varying degree and with flexibility in participation. They suggested professionals should respect their intellectual capacity and encourage them to problem solve. Most patients valued their autonomy not just physically but also in decision making and so suggested participation in goal-setting must be left to the patient's choice.

> *You need to suck the sponge dry and take it in. So it's up to you…but not everybody is [motivated]… –Andrew's Interview.*

> *First of all you should get the patient who really wants to do it.-Denzel in FG1.*

Subtheme 3: Patient empowerment

Patients, in order to be empowered, wanted opportunities to be involved and information from staff with good communication skills. Open communication to share information was recommended to be two way using simple language.

> *I see it as time… time to talk and listen….-Keene in FG2.*

> *Call a spade a spade, don't call it a digging tool. -Katherine in FG1.*

Practical strategies suggested to improve information flow were to use information booklets, hold discussions during regular rounds and document their views in case notes. Documenting patient goals was also supported by professionals. Patients had also preferred to use family as a communication channel in some cases.

Is there a space on MDT form that says what the patient views are?

...so we can ask them before and what they want and so that we have considered each?-SHO in SFG.

It's been okay cause my wife's always asking all the questions and gets all the information. -Peter's Interview

The specifics of information that they wanted was around the roles of professionals, their own role, routines on the ward and the process of goal-setting.

I can't tell you who these people are. I mean about any professional in here….they can actually try and introduce the concept. This is what we try to do with you and this.-Ibrahim's Interview.

On the other hand, some patients suggested information overload might not help; hence they preferred gradual sharing of information, time to absorb information, followed by its clarification.

It is probably too early for giving information. Probably before I go they might say that you need this, you need that, there is a booklet here…-Andrew's Interview.

Professionals agreed on all the above strategies to empower patients. Moreover, they wanted to give patients a voice in the process of goal-setting, by involving them through negotiating goals, guiding or signposting for setting goals and reviewing goals each week. Further, they suggested involving family members or a keyworker role to empower patients.

Decisions are made, so how we communicate to the patient the process. These are your goals, and we will review them on this day… -Andrew's PT1's Interview.

Teasing it out of them… we have to guide them in the matter… -Peter's OT's Interview.

If we can't speak to the patient themselves then which member of the family will be the patient's keyworker who will work with us on goals and do the main communication…-SPC in SFG.

Just somebody to represent the team to say, this is what your goals and your targets are. –Mary's SCN's Interview.

Subtheme 4: Holistic approach

Patients wanted professionals to look at the bigger picture and take into consideration their various needs. This holistic care approach necessitated giving psychological support including hope, reassurance, confidence and encouragement from a key contact who is caring and friendly.

It is… everybody needs self-confidence….

you need to know that there is something better….you need to know that there is something after this otherwise you can become suicidal. -Harry in FG2.

I don't get any encouragement…-Ibrahim's Interview.

Though Harry was speaking hypothetically, such desperation and exposed vulnerability from patients implies a call for support to help them cope. They further wanted a consideration of their extended needs in the community.

> *They have got to ask if you have got any problems at home really. -Melvin in FG2.*

Most strategies that patients suggested were founded on the principle of building a good working relationship implying that this was a pre-requisite to gain patient-involvement in goal-setting. However, only one professional suggested that he would enable a therapeutic relationship based on principles suggested by the patients.

> *Reassure our support and remind him of what he had. Keep him optimistic. – Ibrahim's SHO's Interview.*

Subtheme 5: Professional empowerment

To empower themselves within the goal-setting process, professionals mentioned principles such as guidance and training to carry out goal-setting and reviewing goals.

> *We've got the best intention and we want to do the best for the patient, but how would we involve them in their actual care is probably a little bit off. – Mary's SCN's Interview.*

They further wanted to understand inter-professional roles, work collaboratively and improve communication through collaborative and visible documentation to facilitate PCGS.

If we don't know them (other staff) what they actually are doing and that being educated in other professional roles helps to have same sort of goals. –SN in SFG.

I mean we do joint assessments now… we're asking the same questions. We're looking at different perspectives, admittedly, but then we have to go and fill in the same information…Like how other teams have joint documentation… -Peter's OT's Interview.

4.3 Discussion

The key findings from this study will be discussed briefly in this section. Wider issues and methodological limitations from Study one will be discussed in detail in chapter seven.

4.3.1 Disempowered patients and professionals

A key finding was that patients took a back seat in the goal-setting process despite their keenness to participate. Withdrawal was sometimes observed to be a sign of empathy towards the busyness or workload of professionals, e.g. not wanting to bother professionals or to be seen as troublesome (Huby *et al.*, 2004). It is possible that those patients who appeared to be passive might have been patients who were masking unmet needs and emotional distress. It is suggested that even where the patients appeared passive this might be because they felt unable to influence the situation (Parry, 2004) or because they accepted that rehabilitation was done to them (Wressle, Oberg and Henriksson, 1999). Barnard et al., (2010) go one step further to state that patients act passively and hand over decision making to professionals because they are aware of the imbalance in power in healthcare and want to adopt reasonably acceptable

behaviour by giving professionals the ownership. Nevertheless, patients themselves have contested their passive position in many studies. Patients considered themselves as being self-directed and wanting an active role (Cott, 2004); and they preferred to cope using active problem solving strategies such as physical therapy to overcome their disabilities (Rochette and Desrosiers, 2002; Bendz, 2003).

Previous literature has described patients who were passive and withdrawn as having low motivation (usually branded by professionals) (Maclean *et al.*, 2000) or as non-compliant. Ultimately non-compliant patients get branded as 'bad' patients and were therefore alienated (Rees, Wilcox and Cuddihy, 2002). These professional perceptions might have to be reconsidered in the light of the findings from our studies and the literature discussed above, indicating a need for a deeper understanding of patients' beliefs. Further studies which explore patients' motivation should follow the establishment of the therapeutic relationship and emotional support, to reveal actual factors underlying low motivation.

Additional challenges that contributed to patient disempowerment and were attributable to patients were identified from previous studies. They included patients being unprepared due to limited knowledge (Daniels, Winding and Borell, 2002; Cott, 2004; Suddick and De Souza, 2006), emotional disturbances, self-perceived lower social standing (Bendz, 2000; Huby *et al.*, 2004), and cognitive and communicative problems (Playford *et al.*, 2000; Leach *et al.*, 2010; Lloyd, Roberts and Freeman, 2014). Similar reasons in the patient group in this study either rendered the patients passive or non-compliant. Laver *et al.,* (2010) had interviewed patients regarding their goals at three time points: during acute stay in hospital, sub-acute rehabilitation and six months after stroke. Authors reported that patients had suggested not being ready to set goals during their early days in the hospital at their six-month interview.

However, the data from the early interviews showed that thirteen out of the fifteen participants had raised issues appropriate for goals (Laver *et al.*, 2010). Thus patients recovering from stroke may not be aware of terminology of goal-setting but are able to discuss issues that are pertinent to setting their goals. Additionally, some patient inhibition (not just inability) to participate was identified in this study. Patients in this study wanted involvement in care processes, but, as we have seen were restricted due to factors such as professionals' attitudes and the system.

Disempowerment leading to limited adoption of patient-centredness was not isolated just to patients, but observed amongst professionals. There were limited opportunities for reflection, education and training for healthcare professionals in this stroke unit to implement PCGS. Perceived hierarchy amongst certain professionals limited their autonomy similar to professionals in Baxter and Brumfitt's (2008) study where therapists and nurses expected ratification of decisions by medical staff. Thus professionals in this study expressed disempowerment (cf. Wottrich *et al.*, 2004) and the need for support to improve practice. Additionally, a flexible guideline (ISWP, 2012) which pointed towards PCGS, but lacked recommendations for a model of goal-setting, was not perceived as helpful (Laver *et al.*, 2010) to professionals to implement PCGS. Hence the impetus to 'engage and empower patients' and 'foster development of staffs' ability to improve processes' was as relevant in this setting as in the wider NHS (Berwick, 2013, p.4).

4.3.2 Unhelpful professional practices and perceptions

Another key finding was that the professionals viewed patient needs through profession-specific assessments. Uni-professional assessment in this setting was in line with wider practice in the UK (Holliday, Antoun and Playford, 2005). Goal-setting based on uni-

professional assessments did not enable the identification of holistic goals. Moreover, a specific focus on tasks has previously been found to reduce functional gains in stroke patients since team level functions become fragmented (Strasser *et al.*, 2005). Instead, continual assessments that are multi-professional, along with flexibility in team processes such as goal-setting were recommended for better patient outcomes (Sulch *et al.*, 2000). However, to have integrated multi-professional assessments would be a challenge due to different philosophies and working routines of the professionals. Additionally, whether multi-professional assessments can produce outcomes that can be compared intra-patient and cross-patient is still unknown (Duff, 2009).

Some professionals in this study had perceived that they discussed goals in MDT meetings whereas observations revealed that these meetings discussed the patients' condition and the therapy given. This practice of not discussing goals within formal MDT meetings has been reported in other settings (Gibbon, 1999). In Gibbon's (1999) study it was reported that decisions were made outside of meetings and these decisions were ratified in weekly team meetings. Whether patients' goals were defined during therapy or assessment slots as reported by professionals in our study is a question that cannot be answered directly through this work as therapy sessions were not observed as a part of this work.

4.4 Summary of chapter

This multi-method study revealed that the majority of the components of patient centredness were adopted to a limited extent in the process of goal-setting in this setting. Professional, patient and system-related factors responsible for this limited adoption were identified. However, this study also identified strategies that could help improve PCGS. The outcomes of

PCGS are not evident from this study due to limited adoption; however, the lack of patient-centredness seemed to have caused frustration, negative experiences, and ineffective communication. This situation implied that there was a need for developing holistic processes for PCGS if its effects were to be studied. Hence, based on the findings from this study and the systematic review, developmental work was carried out and is described in the following chapter.

CHAPTER 5

DEVELOPMENT OF A RESOURCE FOR PCGS

5.0 Introduction

The findings from wider research and Study one revealed that many aspects of patient-centredness were adopted to a limited extent (Rosewilliam, Roskell and Pandyan, 2011; Rosewilliam *et al.*, 2015). The key limitation identified was the lack of a comprehensive and structured method to implement aspects of patient-centredness within a system that disempowered patients and professionals. However, the above studies also revealed strategies that could help. Thus, it was decided to build a resource that would be based on patient-centred principles. The process of developing the resource and the resource itself will be described in this chapter.

5.1. Designing the resource

The challenges identified to PCGS in Study one were at various levels involving the professionals' behaviour, patients' behaviour, collaboration within the team, structural deficits and the way the goal-setting process was organised. It was envisaged that in order to improve process the goal-setting process needed to be modified taking into consideration the multiple factors influencing this complex situation. To enable this development, it was decided to gain understanding of theory behind change processes and then develop the new resource and its components.

5.1.1 Theoretical understanding of change process

Lewin's 'planned approach to change' which has been used for management of change in the NHS in the UK, was considered as foundational to this part of the research (NHS Institute for Innovation and Improvement, 2006-2013; Antwi and Kale, 2014). The NHS Institute for Innovation advocates analysis of the factors (forces) that need to be altered to produce change based on the 'force field theory' an interdependent theory within planned change (Burnes, 2004). Study one had served to analyse the forces within the field and helped to identify aspects that required change. Subsequently, Lewin's three stage model of change was considered appropriate to enable patient-centred behaviour within the group of professionals working in this setting. The stages and constructs within this model (Schein, 2002) have been presented in table 5.1 and the relevance of these constructs has been discussed following this.

Table 5.1. Stages in planned change

Stage	Purpose	Constructs
Unfreezing	Creating a motivation to change	Disconfirming status-quo Creating survival anxiety Providing psychological safety
Change	Change involving cognitive redefinition through improving awareness of the meaning and breadth of concept.	Scanning for solutions Setting new standards
Refreezing	Stabilising new behaviour within group.	Internalisation of the new understanding, standards and solutions.

According to Lewin's theory, steps taken to diagnose problems also serve as interventions (Schein, 1996). They can cause awareness and motivation but can also unduly cause anxiety and guilt in professionals involved in the process. Interviews in Study one can be considered as one such 'diagnostic intervention'. This part of the research created awareness amongst the professionals and initiated reflections on their individual practice. The questions in the interview were set up broadly so as not to cause premature 'survival anxiety or guilt'(Schein, 2002, p.36). However, some of the respondents had reflected on their personal perceptual and behavioural limitations. Thus 'unfreezing' or disconfirmation of their beliefs, about their practice, was initiated even before the change process relevant to the new goal-setting method was structured. Further unfreezing was possible during researcher's presentation of study

proposals and feedback on the findings of the studies during in-service training sessions (example in appendix 5.1).

Disconfirmation leading to creation of survival anxiety (related to their following of RCP guidelines and quality of care delivery) was done using in-service training programmes where the findings from the first study were used to highlight the gaps in their practice. At the end of these in-service programmes professionals' feedback acknowledged their shortcomings and need to change practice to align with recommended guidelines. To minimise the psychological impact, group work was used during development of the resource (using focus groups in Study one) and during training. It was felt that participants might find it easier to acknowledge their anxieties to each other and feel supported in the group. Additionally, working within their group to develop strategies and tools based on ideas from professionals (scanning) (Schein, 2002, p.36) for the resource could give them a sense of ownership of the change tools.

The second stage of 'change' was to restructure professionals' thoughts, perceptions and attitudes and could involve relearning the meaning and breadth of the concept of PCGS. This was attempted through design of the training material and the tools. The training material aimed to help participants redefine the concept of patient-centredness. Hitherto it seemed the norm had been that the professionals set goals in the best interests of the patients, whereas the training programme could introduce other aspects of patient-centredness, in effect through acknowledging that patients could and should discuss what they felt their best interests were. Further, providing positive examples of patient-centred practices within the setting and involving an 'opinion leader' (clinical lead) were proposed to reinforce their readiness to change.

The last stage, according to this theory, is 'refreezing', i.e. making the new behaviour the norm. Since the application of the T-PEGS was short term and was planned to be undertaken only with a few professionals, refreezing was not formally attempted in this study.

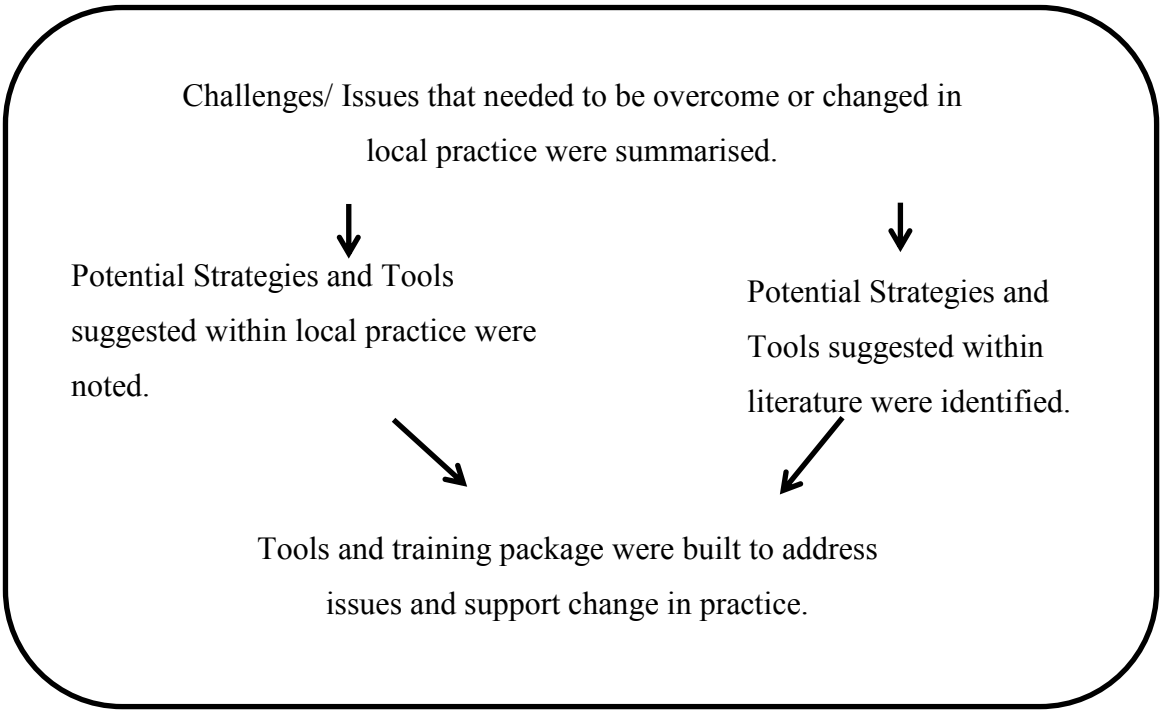
5.2 Process of development of resource

Due to the complexity involved at various levels, the format of multiple interventions 'that can act independently and interdependently' i.e. a complex intervention in Medical Research Council's terms (MRC, 2000) was chosen. Multifaceted interventions have been shown to better influence behaviour changes in healthcare compared to single interventions (Bero *et al.*, 1998). Therefore it was decided to develop a training package which would create awareness of the issues in practice and encourage healthcare professionals to modify behaviour. Additionally, a resource which included ideas and practices (tools) that will help professionals to intervene in a number of ways to improve PCGS was proposed (NHS Institute for Innovation and Improvement, 2006-2013). Though linking psychosocial theories might be a good way forward in building complex interventions for change, this has not been evidenced as yet (Sales *et al.*, 2006). Hence a pragmatic approach to building the complex intervention, was adopted for this study (Greenhalgh *et al.*, 2004; Kochevar and Yano, 2006). In effect therefore, this study takes a common sense approach (Levack *et al.*, 2006a). Nevertheless, attempts have been made to relate pertinent psycho-social constructs to the interventions developed, in the discussion chapter, to highlight possible mechanism of action of these interventions.

Within the resource, tools to overcome challenges in the local setting were built based on findings emerging from Study one which were then transformed into practice activities,

guided also by knowledge from the literature. In addition to the strategies identified from this specific context, research evidence (from Chapter 2) was examined to either support or complement the above strategies. This integration of research evidence with findings from the study was done to encourage evidence based clinical practice. Moreover, using evidence from empirical studies has been found to facilitate improved uptake of strategies for change in primary care (Grol *et al.*, 2007). Thus the resource, a toolkit currently named T-PEGS-Toolkit for Patient-centred and Evidence-based Goal-setting for Stroke was developed through integration of theory and local empirical findings. The logical steps involved in the development process are depicted in figure 5.1.and described following this figure.

Figure 5.1: Process of development of T-PEGS



5.2.1 Issues that required change

Analysis of the findings relevant to limitations in current practice highlighted issues that warranted change. These can be broadly classified as related to professional behaviour and patient behaviour and are summarised as follows. Firstly, it was recognised that a person's professional behaviour might suffer because of the risk of routinisation (e.g. the use of structured assessments in an unreflective manner), of the inhibiting influence of hierarchical structures, contextual factors such as the acute setting and by personal beliefs, perhaps about one's own level of expertise. And secondly it was recognised that the behaviour of patients might be passive, influenced by the limited information and opportunities provided and their beliefs about their recovery, level of confidence and the perception that professionals were unapproachable.

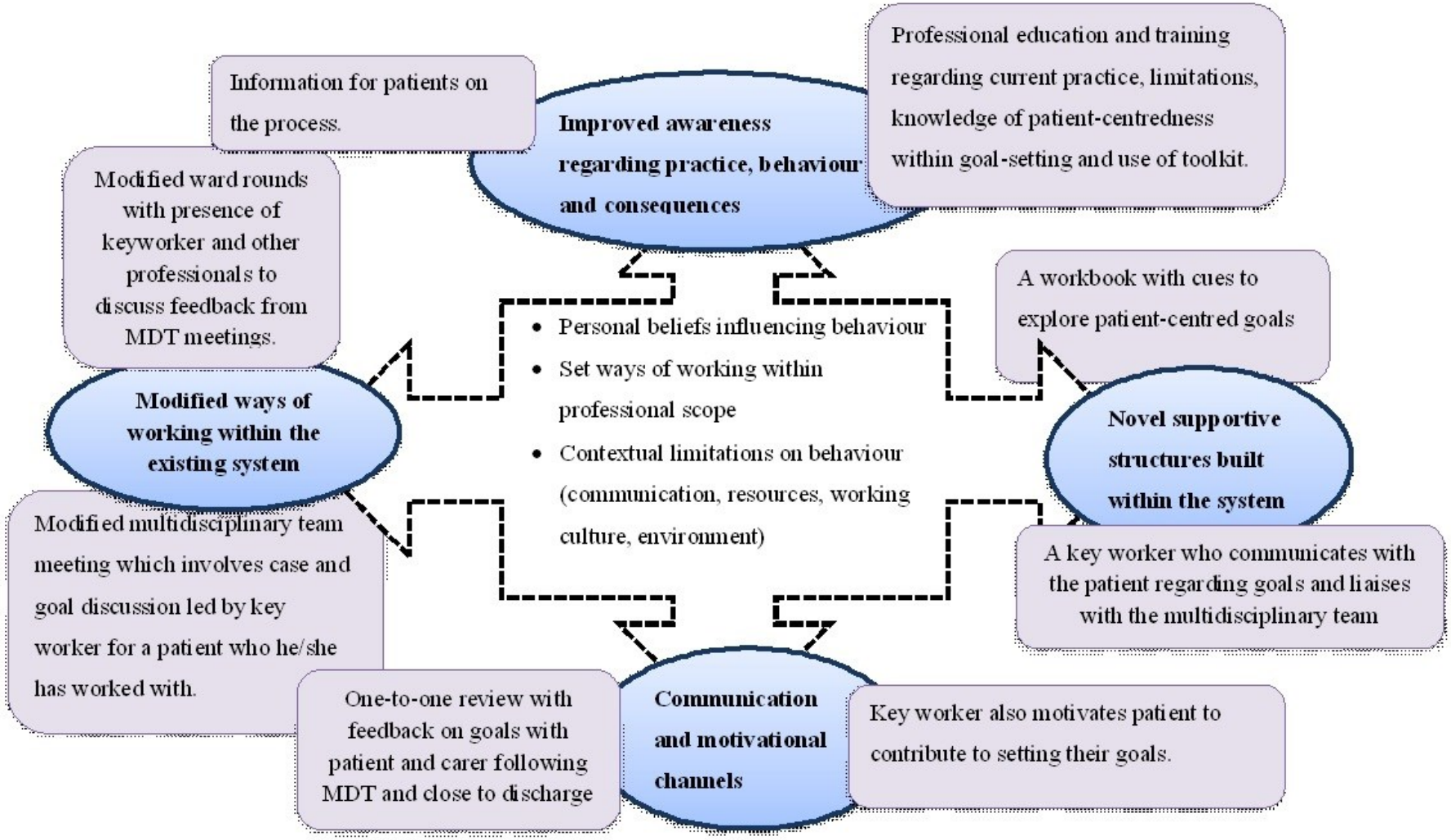
5.2.2 Strategies for change

Strategies were voiced by patients and professionals independently; yet there was a considerable overlap. For example, the strategy of using a keyworker to facilitate communication within team and between patient and team was considered potentially helpful by both groups. Apart from the above strategy to improve communication and motivation, the other strategies from Study one and the literature were broadly classified as, those which improve awareness amongst stakeholders of their behaviour and its consequences, to create new structures within the system and to change routine ways of doing tasks.

Detailed information on the issues around the adoption of patient-centredness, a summary of the challenges, the potential strategies and tools identified from Study one, together with the strategies and tools from the literature have been tabulated in appendix 5.2. This detailed table

was used to logically develop and justify the T-PEGS; a simpler visual representation was created to show how all of this information fits together (figure 5.2)

Figure 5.2: Figure showing the issues that needed change (in white box), strategies (in blue ovals) and tools (in purple rectangles) developed in Study one and from literature.



5.3 Description of tools within T-PEGS

Tools were built specific to the context (Sales *et al.*, 2006) and requirements. Formats that have been shown to be effective in facilitating behaviour change were adopted (Bero *et al.*, 1998). Bero et al's (1998) review found that interventions in the interactive format, including reminders and multifaceted approaches, were consistently successful. Hence the tools were built observing these aspects. However the reliability of the educational/training part of the programme was carefully considered since education and training may not always be optimal for transfer of skills that are complex and meaningful such as patient-centred behaviours. This is due to intervening factors such as workplace practices, previous learning and life experiences (Skelton, 2016). Yet, previously, educational principles using reflective, interactional, learner-centred and small group discussions were found to improve patient-centred behaviours in clinicians (Berkhof *et al.*, 2011). Hence these educational principles were adopted for the initial training. The two parts of the T-PEGS are attached as appendices 5.3 (Training Material) and 5.4 (Tools for Change). A brief description of the tools including their purpose and structure, and how they were applied is below.

The first part of the T-PEGS to be developed was the professionals' training programme (appendices 5.3 a to e). The purpose of the training programme was threefold: To enable reflection on practice and behaviour, to create awareness of current practice and limitations in professional behaviour, and to educate and train professionals in goal-setting, patient-centred practice and the implementation of the T-PEGS. The training programme was planned as half day workshops with three interactive sessions. It was delivered by the researcher and supported by a senior clinician within this MDT. The first session was to educate the

professionals regarding the need, theoretical evidence for, and current practice of goal-setting, and to draw attention to how limited the adoption of patient-centred approaches was within practice (appendix 5.3 a). A brief overview of the concept of patient-centredness was delivered to orient professionals to the approach. A summary of a case study from Study one within this setting was given as a paper case to enable them to reflect on the holistic perspective of the concept, and its limited adoption in this particular case (appendix 5.3 b). The second session was built to gain a deeper understanding of the components within the concept of patient-centredness (appendix 5.3 c). This was integrated with a reflection on more paper-based cases developed from previous findings (appendix 5.3 d) and one internet-sourced video at (http://www.pilgrim.myzen.co.uk/patientvoices/flv/0072pv384.htm)[5].The third and final session within the training programme (appendix 5.3 e) introduced the tools within the T-PEGS, offered a proposed pathway for using the tools and gave the individual T-PEGSs to participants for use in the evaluation (Study two) that followed.

A resource, novel to this setting, introduced within the process was the role of the keyworker (KW). A professional who had input into a patient's care was asked if they could be a keyworker for that particular patient. Professionals from different disciplines who volunteered to play this role were trained in the use of the T-PEGS in the previously discussed training programme. Their responsibilities were explained to them during the training and given in print for future reference (appendix 5.4 a). The purpose of having a keyworker was to act as the key contact person for the patient and his/her family regarding the goal-setting process and to act as the liaison between the patient and the multidisciplinary team. Keyworkers acted as the motivators and guides, and as a communication channel within the goal-setting process.

[5] Copyright 2015 Pilgrim Projects Limited licensed under a Creative Commons Attribution-NonCommercial-NoDerivs 2.5 License.

A patient information leaflet was used to motivate and inform the patient and his/her family about the goal-setting process. The leaflet had information about the aims and meaning of the process, steps within it and opportunities to get involved in the process (appendix 5.4 b). The information was made patient-friendly by keeping it minimal, using simple language and using a question and answer format along with pictures to gain interest from the patient. It was printed on high quality paper used for brochures to withstand the wear and tear. It was planned that the leaflet would be delivered and accompanied with explanation about the process, by the stroke coordinator or the keyworker.

The next tool was the goal-setting workbook to be used by the patient, family and keyworker (appendix 5.4 c). The purpose of this document was to motivate the patient to think about goals (goal intentions), to provide opportunities for their family or carer to get involved in the process, and to explore wider aspects of the patient's life to gain an understanding of their current needs and future goals. The additional purposes were to serve as a record of patient goals and queries, to break down broad goals, link therapy goals to patient goals, and to review goals and provide an opportunity to discuss information about discharge. The document was structured as a multiple page questionnaire with space to fill in responses, and was made patient friendly by using simple language and colour coding to indicate the different timelines for its use. The workbook was delivered by the keyworker to the patient. The patient and family/carer were encouraged to write on the document in the first instance. The keyworker used this document to discuss the patient's goals in the MDT meeting. Information was added on the document by the keyworker and patient as and when required.

An opportunity was created within the routine multidisciplinary team meetings for the keyworker to present the patient's situation and goals, instead of the routine, where cases

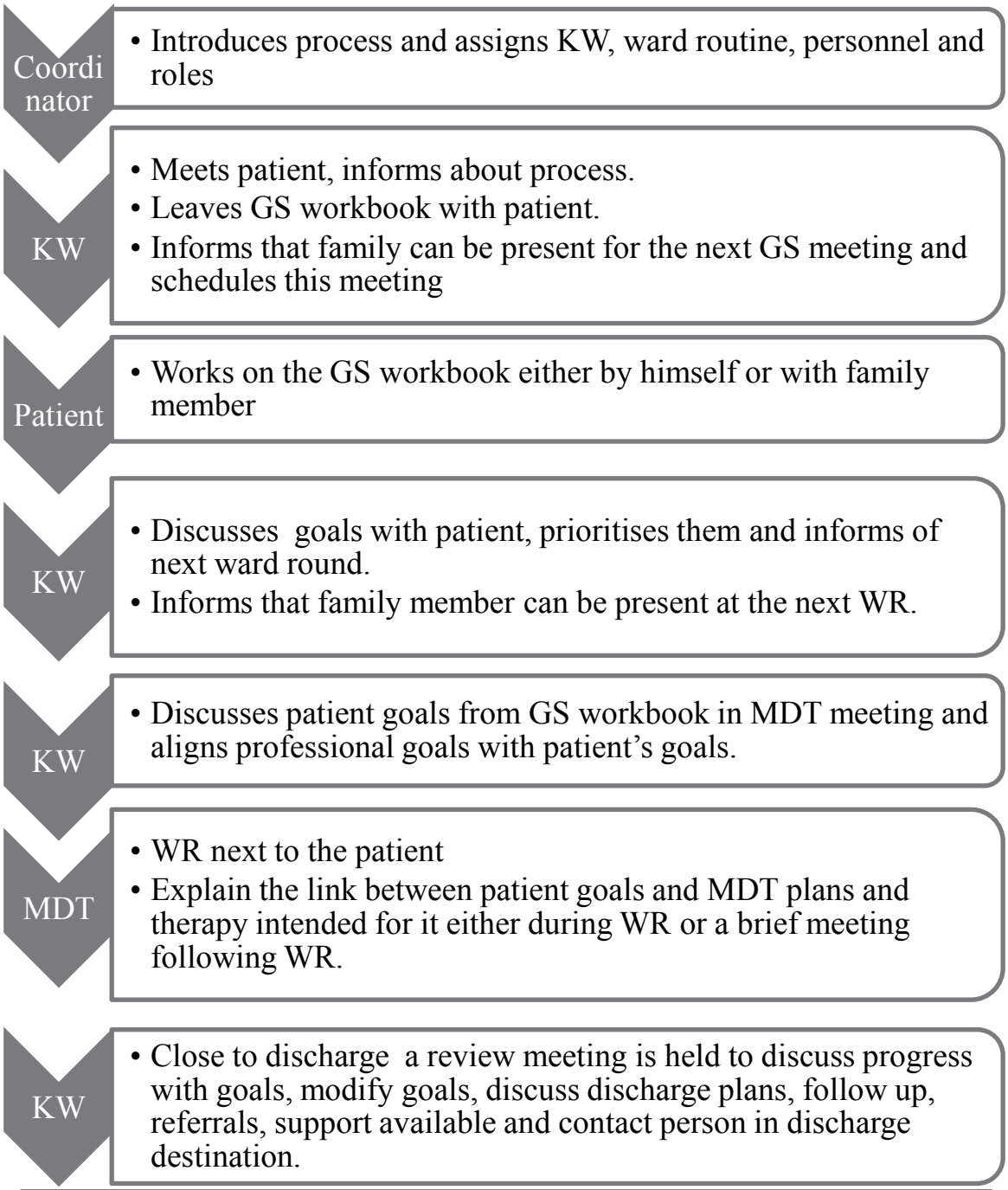
were presented by the doctors. The purpose was to communicate the patient's goals to the rest of the team members, decide on professional plans and interventions and eventually link them to the patient-voiced goals. The structure of communication in the MDT meeting was left to the keyworker based on their individualistic styles, but they were informed about essential actions to be carried out during this opportunity within the MDT meeting (described in appendix 5.4 a).

An opportunity was created for the patient and if desired his/her family/carer to get involved in discussing needs and goals with the MDT members during ward-rounds. The purpose of this opportunity was to integrate the patient within the team and establish a forum for communication between patient, family and the professionals. The keyworker was responsible for inviting the family and advocating for the patient in the ward-rounds. There was no predefined structure to this meeting except for the presence of the keyworker and arranging for the family's presence during the ward-rounds.

Two other meetings between keyworker and patient were set up as part of the T-PEGS. The purpose of the first of these meetings was to give feedback about the MDT's discussion about the patient's goals and explain the link between these goals and professional plans. The purpose of the last meeting was to review the progress with goals, discuss informational needs and plans about discharge. The keyworker planned and set up these meetings (appendices 5.4 a and 5.4 d). Cues for discussions during these meetings were given in section two and three of the workbook (appendix 5.4 c).

The proposed sequence for the application of the tools within the T-PEGS have been presented in figure 5.3

Figure 5.3: Proposed sequence of application of the T-PEGS indicating roles and responsibilities



Legend: KW Keyworker; GS Goal-setting; MDT Multidisciplinary team; WR Ward-rounds

5.4 Summary and conclusion

The development of the T-PEGS and has been described in order to improve transferability into practice. However, attempts to transfer application of T-PEGS should take into consideration the contextual factors and limitations discussed in Chapters six and seven. The theoretical underpinning for the application has also been described so that readers can understand the proposed mechanism of action, the feasibility of changing behaviour and process within this context. Following this development, Study two was carried out to evaluate the appropriateness and feasibility of applying the T-PEGS which will be described in the following chapter.

CHAPTER 6

STUDY TWO

6.0 Introduction

A resource for the application of PCGS was developed following integration of findings from Study one and the systematic review as described in the previous chapter. The Study two was then designed to apply the resource (T-PEGS) in practice, appraise whether its application influenced the adoption of patient-centred principles, the feasibility of its application in practice, and to identify potential outcomes. This chapter will describe the methods used to apply T-PEGS and evaluate its application, followed by the findings and a brief discussion of key findings.

6.1 Methods

The overall study design, data collection and analysis methods for the evaluation of the T-PEGS was very similar to Study one, and have been described in Chapter four. However, the information related to the modifications done within these methods to meet the study's objectives and to improve methodological quality will be outlined in this section.

6.1.1 Ethics

Approval was granted for this study from the National Institute for Social Care and Health Research, Research Ethics service (LREC Refno13/WA/0275). The Birmingham Clinical Research Office granted approval for conduct of the research and access to research site for

this study (ref nos. RRK4911). The approval letters for the studies are attached as appendices 6.1 a and 6.1 b.

6.1.2 Setting

The T-PEGS was applied within the same acute stroke unit in west Midlands where Study one was carried out. Routinely goal-setting in this unit was suggested to involve discussions about goals during therapy sessions, in multidisciplinary meetings and recorded in patients' notes. Further details about the setting and routine practice have previously been described in section 4.1.2.

6.1.3 Participants

Patients and staff were purposefully sampled based on the inclusion and exclusion criteria set out in table 4.1 in order to be able to contribute to the study. In addition to the criteria listed in this table, for Study two, patients should have a predicted length of stay of more than three days so that the different steps in T-PEGS could be applied as a part of their care. This ensured that a patient participant's case was discussed in minimum one MDT meeting based on the guidance in T-PEGS. Prediction of length of stay for patients was made by the clinical lead or following discussion with medical personnel. Thus pragmatic decisions regarding patient inclusion were made by the researcher collaboratively, by sharing responsibility with the clinicians in the study setting. As a result, clinical care decisions were always considered to take precedence over research participation.

Staff participants were recruited prior to patient recruitment since these staff needed to be trained in the use of T-PEGS. Then patients who were being treated by these staff were assessed for eligibility, discussed with the concerned staff participants and then recruited.

Both staff and patients were given participant information sheets (appendices 6.2 a and b) to understand the study following which consent forms were signed by the participants (appendices 6.3 a and b).

6.1.4 Application of the T-PEGS

Following recruitment of staff to apply the T-PEGS, they were trained to apply the T-PEGS with patient participants. Prior to the actual application of the T-PEGS in practice, the training programme was tested with a group of qualified physiotherapists who were undertaking their doctoral studies. Following this, the training programme was also delivered to the research supervisor who was a specialist in education to appraise the delivery of training programme. These were done to appraise the comprehensibility of the teaching material, the structure of the components, the communication of the researcher and the time taken to deliver the training.

As a result of the pilot and screening by research supervisors, the following changes were made to the training programme.

- A video clip from the internet was added in addition to the paper cases to improve variety of cases and formats for reflection during training.
- The content on slides was reduced to lessen information overload.
- Based on discussions, it was decided that during training for professionals it will be highlighted to them that the goals for patients were based on normality as trying to regain status prior to stroke. However, professionals must try to reiterate normality as 'normality within restrictions' to avoid unrealistic expectations and frustrations during goal discussion and review.

- The time spent on talking by the researcher was reduced; instead it was replaced by brainstorming on problems by professionals at various points.

Following the refinement of the T-PEGS, the Study two was introduced to the MDT in February 2014 during a routine team meeting. Within this session, case studies from Study one (example in appendix 6.4) were used to create awareness about limitations in practice, and to initiate thinking about patient-centred goals. Volunteers for applying and evaluating the T-PEGS in practice were recruited for this study after this session.

In March 2014 the first part of the T-PEGS, 'the training program', was delivered to the professionals who had volunteered participation within the hospital settings. This was delivered by the researcher as a small group workshop and was supported by the chief investigator on site. Following the start of the study in the setting, once patients were recruited into the study, one professional for each of the patient participants was approached to act as the keyworker. This matching of keyworker to patient was done based on the professional's engagement in routine care of the patient to reduce additional burden on the professional. For example, a patient with primarily increased physical deficits who needed physiotherapy was matched up with the physiotherapist as his keyworker. The professional was introduced to the patient as the keyworker, from which point the researcher acted as the facilitator (arranging appointments in some cases), guide for the professional and observer in the process. The T-PEGS was then applied during care of the patient participants using the proposed steps as set out in figure 5.3.

6.1.5 Data collection

In order to evaluate appropriateness and feasibility of applying T-PEGS, data was collected using methods similar to those in Study one. The data was collected through interviews with

the professional and patient participants, observation of their MDT meetings, goal-setting meetings and ward rounds and analysis of documents related to goal-setting. Since the purposes, application, advantages and limitations of each of these methods have previously been described in table 4.2. the variations in the application of these methods for this specific study have been highlighted here.

a. Interviews were conducted, with professionals in the hospital and for patients in their discharge destination (home or hospital). Carers were present during few of these interviews. The question guides previously used were modified to include questions relevant to evaluation of the goal-setting process using T-PEGS (appendix 6.5).
b. Documents (e.g. case notes) that contained goals or plans for patients' rehabilitation were collected and scrutinised. In addition to the routine documents used on the ward by different professionals, the goal-setting work book developed for the T-PEGS was also analysed.
c. Ward-rounds (WR) and Weekly Multi-disciplinary team meetings (MDTM) were observed, and field notes made. Since observations for Study one were non-structured, they were found to be influenced by selective attention to data. Therefore, for Study two, a guide focusing on what to observe in the meetings was developed based on the literature around observation in stroke (Gibbon, 1999; Pound, Sabin and Ebrahim, 1999) (appendix 6.6). The guide helped to reduce subjective observer bias (Kawulich, 2005) and recorded what was necessary.
d. A Focus group was held with staff who acted as keyworkers (SFG).
   This was done specifically to gain views of professionals about the application of T-PEGS and its refinement. The staff were questioned on their understanding of the new method, facilitators, barriers and refinement strategies for this method (appendix 6.7).

This study only had a staff focus group but not a patient focus group due to pragmatic reasons such as patient participants being discharged at different times to different destinations and their busy schedules.

6.1.6 Data Analysis

The tapes from staff interviews and staff focus groups were transcribed by professionals from transcription services, but the researcher read and reread the transcripts to immerse in the data. The interviews from patients were transcribed by the researcher which improved immersion and engagement with the data. Similar to study one data analysis was carried out using manual coding and interpretation rather than use of software.

Descriptive and interpretative codes were assigned to chunks of data; these codes were largely based on codes from study one if the emerging concepts were broadly similar. These codes were clustered under broader categories (sample given in appendix 6.8). To improve rigour of analysis a second analyst not involved in this study coded two of the interview transcripts which were then compared to the researcher's coding and interpretations. The codes and categories from cases were written up as descriptive summaries by switching between coded documents. No cognitive maps or spider diagrams were made for this step unlike in the Study one due to better experience and familiarity of the general patterns within data (Miles and Huberman, 1994, p 79). Analytical memos were written alongside these descriptive summaries for each of the cases.

With regard to the data from documents, it was summarised in tables with information about who filled in, details of event, professionals' goals and goals for rehabilitation similar to study one. However, the analysis for this study adopted the open coding and categorising of data within these summarising tables, to make the analysis more robust and in line with the analysis of data from other sources (Bowen, 2009) rather than adopting the summarising strategy used for Study one (sample given in appendix 6.9).

The next step was to display chunks of data from the descriptive case summaries in matrices in which the dimensions and components of patient-centredness were set out similar to Study one (Miles and Huberman, 1994,p 127; Rosewilliam *et al.*, 2015). These matrices were then screened to identify the extent to which each component was adopted in each case. This was scoped out based on the levels of congruence classified as Reasonably good congruence, Partially congruent, Incongruent and Irrelevant (described elaborately in section 4.6.1.3). Congruence arising from triangulation of the multiple sources of data within these cases, was considered important to draw inferences regarding the influence of the T-PEGS.

The next step was to summarise these patterns of congruence in each case and gain an overview of extent of adoption across cases (intra case analysis) based on distribution of cases across the continuum. The case numbers were clustered in a table under different levels of congruence for the different components of each dimension (appendix 6.10). This information was then used to analyse change in the extent of adoption of aspects of patient-centredness before and after application by comparing with similar table from study one (appendix 4.11).

In order to answer the other questions regarding feasibility of applying the T_PEGS, three tables were used to display codes, categories and summarised data that were relevant to factors influencing application from clinicians, patients and feasibility of application

(appendices 6.11 to 6.13). These tables were screened to analyse patterns, similarities and differences (Yin, 2003 pp 156-160) to derive interpretations and themes relevant to answer the question using strategies set out in table 4.4. The strategy to explore inter-relationships between variables i.e. networking between variables or concepts to derive reasonable belief that A could have caused B was adopted in the evaluation of factors related to feasibility. For example, acceptability was linked to satisfaction and appreciation; but, behaviours of patient and professionals seemed more relevant, than expressed satisfaction in determining acceptability of the toolkit (section 6.2.3.3).

An audit trail for deriving these subthemes and themes from categories and data codes was developed to illustrate the logical link between codes, categories and themes (sample presented in appendix 6.14). The themes and subthemes have been presented in the following results section 6.2.

6.2 Results

6.2.1 Results of the recruitment process

A total of 101 patients were screened for eligibility to participate. The results of the screening process along with reasons for rejection are described in table 6.1.

Table 6.1. Reasons for rejection at the stage of screening for eligibility

	Reason for rejection	**Numbers rejected**
1.	Did not need therapy or were to be discharged within the next few days	34
2.	Cognitive issues	13
3.	Severe strokes (drowsy, non-responsive)	13
4.	Severe communication problems	11
5.	Other serious illnesses like cancer	7
6.	Other substantial medical issues	6
7.	No clear stroke diagnosis	2
8.	Did not speak English	2
9.	Relevant keyworkers or consultants were not available on the ward	4
10.	Functional stroke	2
11.	Recently recruited to another trial	1
12.	Refused participation since he felt that he couldn't contribute much	1

Five patients were recruited for the study who were involved in the application of T-PEGS and were interviewed following this. Five staff from different professional disciplines were approached and following their consent to participate were trained in the application of the T-

PEGS. These five staff participated in interviews for the case studies and in the staff focus group (SFG). The patient interviews lasted between 14 and 27 minutes, the professional interviews lasted between 15 and 26 minutes. The staff focus group lasted for 50 minutes. The characteristics of the patient participants, staff participants, the meetings and documents analysed are summarised in the table 6.2.

Table 6.2. Characteristics of patients, corresponding professionals, their goal-setting meetings and documents within the case-studies and participants in Staff Focus Group

Pseudonym	**Diagnosis**	**Age**	**Ethnicity & Gender**	**Occupation**	**Social Status**	**Length of stay**	**Staff interviewed and grade**	**Goal-setting meetings**	**MDT meeting**	**Ward-rounds**	**Therapy & MDT records**
Patsy	Functional Stroke	49	White Female	Receptionist in medical/ Mental Health services	Lives with husband	4 days	OT- Band 7	1 15mins	1 7 mins	1	1. CAS 2. CS 3. OT-NSA 4. SU-MDT-MG 5. TR
Jonny	Lt ICD thrombus-crescendo TIA→ Perioperative infarct	80	Black Male	Retired as steel fabrication engineer (private)	Lives with wife and son lives close by	12 days	Staff Nurse-Band 6	2 67mins	1 7 mins	1	1. CAS 2. CS 3. SU-MDT-MG 4. TR

Mohammad	Right MCA infarct	71	Asian Male	Retired teacher	Lives with wife and son	10 days	PT- Band 6	3 31 mins	1 12 mins	1	1. CAS 2. CS 3. SU-MDT-MG x 3 4. TR 5. PTR 6. STC
Carson	Right MCA thrombus	52	White Male	Unemployed	Lives with parents	11 days	SALT-Band 6	4 54 mins	1 10 mins	2	1. CAS 2. CS 3. SU-MDT-MG x 2 4. TR 5. PTR
Claudia	Internal capsule infarct	42	Black Female	Unemployed in higher education	Lives with children and partner	18 days	Stroke coordinator nurse- Band 6	4 40 mins	1 6 mins	0	1. CAS 2. CS 3. SU-MDT-MG x 3 4. TR 5. PTR

Legend: Collaborative assessment sheet (CAS); Continuation sheets (CS); OT neurological screening assessment (OT-NSA); Stroke Unit MDT meeting goals (SU-MDT-MG);Therapy record (TR);Physiotherapy treatment record (PTR); Stroke transfer of care (STC)

6.2.2 Does the application of the T-PEGS make a difference?

The findings from the case studies following the intra-case analysis are presented here. These findings relevant to the level of adoption of components[6] of PCGS in practice are described in the following two categories.

Category 1: Components of PCGS that were observed to show considerable improvement

Overall there was a better therapeutic relationship linked to the empowerment (provided by the sharing of information) and the bio-psychosocial approach compared to the pre-application stage. These components where there were greater improvements will be discussed below drawing attention to the limits in these improvements.

Within the cases observed, there was good 'Congruence in goals' since patients were aware of their goals, patients' goals were recognised by keyworkers, discussed in meetings and patient agreed goals were recorded in notes. Additionally, interventions were observed to be implemented for the goals prioritised by patients. Ultimately, involvement in the process was reported by some patients to reduce their stress.

> *"A lot of her issues were around anxiety, coping at work and more of those demanding, complex roles, and I think she might have had a challenge returning to that."-Patsy's KW's interview.*

[6] The specific components of patient-centredness have been defined in appendix 3.1

"OT (KW) presented the case concentrating on anxiety about going back to work… it was decided that later this afternoon clinical psychologist will speak to patient."-Field notes from Patsy's MDTM.

" the information that she gave me was quite soothing, satisfying knowing that what happened inside there (team meetings), I did not know anything about and I was told by somebody else exactly what was going on. So, it was a load off my mind"-Jonny's interview.

Moreover 'personal relevance of goals' was observed to have reasonably good congruence as not only biological and physical needs were considered but psychological and social goals were also set for most cases (as seen in Patsy's case). Though long term 'psychological issues' (which include emotional and cognitive behaviour), were better identified and three of the five patients had interventions relevant to this component, management of immediate 'emotional concerns' was still limited in some cases.

"They (professionals) came out and talked about his mood being low but then decided nothing about it as they perceived that patient was not having any concerns regarding it." Field notes from Carson's WR.

'Leisure' was considered to a greater extent in patients, with some goals set relevant to patients' interests. This was reflected in the better congruence in understanding of patients' 'biography' compared to pre-application when leisure was seldom explored by professionals. However attention to aspects of leisure was still just partial since professionals did not usually discuss these leisure goals.

"Well, a lot of his goals were to get back to his hobbies that he enjoys doing at home, like his baking, going to church, going to the singing in the choir and things."-Jonny's KW's interview.

Yet another component, 'transition to community' was observed to show improved congruence since keyworkers not only identified potential issues following discharge but also set goals relevant to them and discussed possible solutions with their patients.

"I think a lot of them were more from an anxiety point of view and being a bit nervous about the fact he would be going home… the fact that it would happen again and also a lot of medications and obviously follow ups. So they did have a few questions, which I do suppose we answered for him."- Jonny's KW's interview.

It is possible that improvements in above components were a reflection of improvement in components of the dimension *empowerment and sharing responsibility* which are discussed below. 'Active participation', was observed to have improved since patients discussed goals with their keyworkers and had follow up meetings regarding their goals in contrast to the pre-application stage. Moreover, patients also perceived that they were asked for their opinions, plans were made following discussions with them and they had had opportunities to review their goals. Thus the component 'patient as an expert' had improved.

"They asked me yeah."-Carson's interview.

"I have been in hospitals before where you're not sort of encouraged to…you are not involved in their decision making. It's like, "This is what we're going

to." Now, it's more like, "Is this something that you'd like to do?"-Patsy's interview.

Despite this shift, 'active participation' was not recognised by some patients where there were administrative issues (lost documentation and time lapse before interview).

"I hardly remember that…. Perhaps if she has it documented it would be good…"Jonny's interview.

The evidence around active participation can be ambiguous in one case despite the patient being consulted on goals, this patient's belief about the good will and expertise of professionals made him give up the ownership of goals. E.g. Carson had perceived participation in goal-setting (as seen above), but simultaneously expressed that the professional had set his due to their expertise.

"It (goal) was decided by the physios and the doctors….I know that there are good doctors and the physios are good as well. What they say is the best. ".- Carson's interview.

Linked to the above, 'active problem solving' by patients was observed to have better congruence since professionals acknowledged this attribute whereas previously professionals seldom recognised the patients' ability to actively problem solve. The use of the workbook for patients to set goals and opportunities to discuss issues made these skills more explicit. This workbook also seemed to have provided a framework to serve as prompts for the keyworkers to enable problem solving. Hence, these problem solving skills were facilitated by keyworkers ('strengthening problem solving') when they discussed the issues recorded in the workbooks.

"So I sat down with the patient, … he and his family had already thought about what he was previously doing, what he would actually do again, what his current problems were, that sort of thing. So we went through them and discussed them."-Mohammad's KW's interview.

One factor that was perceived by patients to contribute to problem solving was the information given to them. It was observed that there was a better level of congruence in most cases for patients to 'gain informational control' compared to the routine goal-setting process. This was despite the unchanged nature of the challenges such as limited staff presence in the ward-rounds, medical focus of the ward-rounds and its short duration.

"It's helped me to ask questions, whereas before I never asked questions…" - Claudia's interview.

In spite of the improved opportunities to gain information, due to the one to one meetings with the keyworkers, one patient felt that lack of private space for discussion and quick discharge were barriers to gaining information.

"it's difficult to get into such in depth conversation with someone [KW] you've only just met….that probably would stop me saying too much is when there are people around the bed…"-Patsy's interview.

However, following improved exchange of information with patients by the keyworker, there was a better information exchange within the team. Even though the patients were still not part of the MDT meetings, their keyworker liaised with the team regarding their goals.

Moreover the feedback from MDT provided to patient was considered to be a cohesive message from the team.

> *"I think the fact that he and his family could see that this was coming from all of the team, that we all felt this was the most appropriate place."*
> *Mohammad's KW's interview*

> *"She (KW) said about his goals as driving, participating in church, singing, going back home and baking cakes. PT reported that he realises his potential and he is taking it slowly…." Field notes from Jonny's MDTM*

Additionally, the 'multidirectional information flow' extended to the family members who participated in the discussions in two of these cases. They were involved in setting and reviewing goals especially when filling in the goal-setting workbook.

> *"Wife asked about the heparin injections and KW said that it will continue as long as they are in the hospital and move to a new drug when they go home."*
> *Field notes from Jonny's meeting with KW.*

Yet there were the issues around carers being inaccessible or unable to support the patient in some cases.

> *"They are not very healthy now. My mom and dad can't do it." Carson's interview*

Above all, there was an improvement in components of the therapeutic relationship, possibly resulting from efforts to involve the patient. 'Clinicians' attitudes' were positively commented

on by some patients. Patient participants did not voice any negative comments regarding clinicians' attitudes when compared to the participants in Study one and remarked that staff were friendly, empathetic and approachable.

> *"very approachable, and you could tell they wanted to help." Patsy's interview*.

> *"Now for the I-pad started Carson and keyworker said you are pushing it. OT came in and keyworker asked it will be good if they can find a paper for him at the most." Field notes from Carson's meeting with KW.*

There were no reports from patients regarding professional disrespect. Instead patients reported that they perceived respect due to the democratic nature of the discussions, opportunities for clarifications with issues and options being explained. Hence there was a better confidence in professionals, reflected in the shift in perception of 'professional respect' observed in this study.

> *"They are doing their best and taken my point of view into account. So not just from your angle, you try to do it from my angle as well."-Mohammad's interview.*

> *"So yes, freedom to ask, freedom to speak and/or ask any questions I knew was there."-Jonny's interview.*

With regard to professionals, there was a shift in professionals' understanding of the 'patients' psychological world' in that patient values and intrinsic motives were acknowledged and

catered to. In some cases this understanding along with continuity in care provision by a specific professional facilitated acute management or planning for further rehabilitation.

> *"Obviously we could go through his fears, because he had quite a lot of fears… was in extreme pain, he was agitated. It just was nothing like the Jonny I knew beforehand, so that is when I knew that there was something going on. That's why I got the vascular team to see him straightaway..." Jonny's KW's interview.*

This mutual understanding was reflected in the 'bonding' observed between keyworkers and patients where both of them remarked positively about their relationship. Patients appreciated and were satisfied with the time, communication, support and care received not just from their keyworker but overall in the setting.

> *"People offered information. ... So, the information was offered, and we didn't necessarily say "what about this?" They were all just brilliant." Patsy's interview.*

Likewise, professionals who acted as keyworkers perceived that they knew their patients better, felt comfortable working with them and perceived that open communication was possible. Keyworkers along with being more empathetic felt that patients also developed a more realistic view of their potential

> *"Initially, I didn't [think he was realistic] ... But actually as I talked to him a bit more, I think he was real…like he said to me his goal was to be independent, but I went into it a bit more he said he mentioned "oh the physios*

have mentioned a wheelchair that I can use independently," which is realistic."-Carson's KW's interview.

Despite the bonding observed in most cases, Patsy felt that she needed more time to bond with her keyworker since she had been discharged early from the hospital.

Category 2: Components of PCGS whose level of adoption showed minimal to no change

Some components had been adopted to levels ranging from reasonably good extent to least adoption pre-application (refer to section 4.1.1), but these levels did not change much following application. They are discussed below drawing attention to the findings that illustrated these small changes.

With regard to the *individualistic* and *bio-psychosocial approach,* certain components relevant to the 'identification of biological needs' and 'social status' by patients and by professionals showed reasonably good congruence both before and after application. There were goals for most needs especially the biological needs.

"Plan: Chest physio/normal medications/ reattempt cannulation/ encourage oral fluids."-Mohammad's notes.

It was observed that issues that contributed to 'participation' limitation were identified better in some cases and had relevant follow up goals. For example 'economic issues' not evidenced in any of the data sources in Study one were explicitly mentioned in two of the cases. It can be argued that patients in Study one did not have economic issues and hence they did not surface during exploration. However the relationship established through the keyworker

enabled discussion of such sensitive issues in Study two. Moreover, plans to support these issues were noted at least in one case in this study.

> *"OT said that stroke association could help with her social issues and she could get a bus pass for her disability. Clinical lead said if they referred to R from Stroke Association he will help with getting benefits and returning to work etc." Field notes from Claudia's MDTM.*

Similarly, 'habilitation' goals which were considered irrelevant to practice in this setting previously were suggested by two patients (*"venturing into doing things that I probably wouldn't have done before, explore a bit more" Claudia*). However, the professionals did not identify this component.

An understanding of patients' 'subjective experience of illness' had shown some improvement as patients' attitudes and priorities were acknowledged by professionals; but patients' views about their own recovery were not considered by professionals.

> *"you need to know what the patient priorities are, because it tells you whether they're going to engage in therapy or not…. if he had been concerned about his speech or saliva control, I would have seen him for much longer. But I didn't really have any role because he wasn't concerned (about dribbling)."*
> *-Carson's KW's interview.*

With the improvement in understanding of the patient's attitude and beliefs about their health, 'health promotion' also showed better congruence in some of the cases. The need for further information was identified following which relevant information was discussed and

supplemented with leaflets. However the information given to patients was not shared with team members and was seldom recorded in patients' notes.

> *"She (KW) said she will give him a leaflet on warfarin and atrial fibrillation as he has been put on warfarin now."-Field notes from Jonny's meeting with KW.*

One component that was not explored in most of these cases similar to pre-application was 'environmental issues' in relation to home environment. This was probably because these patients were either physically well enough not to have environmental issues or because they were moving to further rehabilitation rather than going home.

Overall, considering the above components, the understanding of a patient's 'biography' and 'sensitivity to different contexts and time' seemed to be adopted to a reasonably good extent prior to and after the application. However, even issues that were not routinely included in assessments pre-application such as pre-morbid hobbies, life roles and psychosocial problems, were understood and considered during care planning in Study two.

> *"Doctor said … she had a small stroke last year and couldn't come for check-up as she had no money for the bus. He said it was not good that patient couldn't come because of money. She should get benefits and that's why he wanted Social Worker to be involved straight away." Field notes from Claudia's MDTM.*

Similarly, with 'sensitivity to contexts and time' there was additionally a better understanding of patients' responsibilities at home, and therefore, goals related to home even for those who were transferred to further rehabilitation facility were considered.

> *"...the major thing was getting home to his parents and helping them with gardening and chores, that kind of thing."-Carson's KW's interview.*

Certain components related to *empowerment and sharing responsibility* and *building a therapeutic relationship* did not show much change following application. 'Maintaining positive hope' was one of them. Patients still voiced their hopes about their recovery. However professionals did not explicitly discuss hopes around recovery except in two cases where the professional had identified patient's hopes related to their goals.

> *"He hopes that if he worked hard he can get back to normal life and perhaps seek employment again."-Psychologist's notes for Carson.*

Likewise, 'self-efficacy beliefs' were discussed by patients but not explored by professionals in either study. Though most patients expressed beliefs that they can achieve goals based on their ongoing recovery, one patient doubted her confidence, which was not identified by professionals.

> *"I felt that I sounded crazy when I would explain how I felt, how the stroke was, and what it did. So, I felt like I didn't understand what I'm saying.... I just wasn't sure if I was bringing it across for everybody to understand" Claudia's interview.*

The component 'respect for patient autonomy' showed good congruence similar to the situation in the pre-application stage. Patients had set goals relevant to independence in activities of daily living, mobility and self-care which were aptly identified by therapists and keyworkers yet again, possibly because they fitted in the professional remit.

> *"Doctor asked what his goals were for this week. PT said walk with aid. Doctor asked whether he needed walker. PT said he might not benefit from it and will need a stick."-Field notes from Mohammad's MDTM.*

However it was observed that 'executional autonomy' was seen to lead to unsafe experiences in two of the cases.

> *"Patient found on floor in leaning position, patient reported hitting left shoulder but not head…. tried to get into bed without help"-Mohammad's notes.*

Whereas 'decisional autonomy', in this study showed slightly better congruence in that professionals encouraged and supported patients' decisions in three of the cases.

6.2.3 Feasibility of application

The second focus of this study was to explore the feasibility of applying T-PEGS in practice. The issues related to practical application of the T-PEGS such as execution, practicality, demand and acceptability, and integration within practice will be described in this section. These aspects of feasibility described by Bowen *et al.*, (2009) have been explained within the following sub-sections.

6.2.3.1 Execution

Applying the T-PEGS (execution) as set out originally (see figure 5.3) i.e. 'fidelity', was evaluated to see the extent to which this process can be implemented. Also the ability of participants to use the workbook was considered from the data. Professionals who acted as keyworkers explained the process to the patients in their first meeting except for one case where the keyworker was unavailable on the ward; this responsibility fell to the researcher. In all of their second meetings keyworkers clarified information that had been filled in by the patients in the workbook, demonstrating motivation on the part of patients and professionals in the execution of the T-PEGS.

> *"Mohammad had written all the information on the workbook left him the previous day. KW went through all the questions. Mohammad agreed with everything written on it. He added more information for some questions."*
> *Field notes from Mohammad's meeting with KW.*

Moreover, staff suggested approachability ('nice and comfortable to work with'), open communication, ability to suggest goals and confidence as patients' attributes conducive to applying the T-PEGS. Patients seemed to agree; lack of confidence in one's communication skill and lack of immediate bonding were raised by patients as deterring factors to discuss their concerns.

> *"He would have probably opened up quite a lot, and told us quite a lot of his goals anyway because he was quite confident with talking."-Jonny's KW's interview.*

"I just wasn't sure if I was bringing it across for everybody to understand how the feeling was…"-Claudia's interview.

Keyworkers suggested that the workbook was easy to use, with its conversation starters and stated they were able to derive themes from the conversation. Yet, one keyworker perceived otherwise.

"…for some people quite complex in language… it's the time that it might take to do this relatively complex panel of questions" Patsy's KW's interview.

Keyworkers explored patients' preferences, pre-stroke status, familial roles, health beliefs and psycho-social aspects in the goal-setting meeting. They then set up goals, interventions and referrals relevant to the patients' priorities in most cases. Options were discussed with patients.

Patients' goals and concerns were discussed in MDT meeting in all of the cases except one case where the keyworker slipped back to profession-specific goals. Support for patients following discharge was arranged through referrals to external agencies and follow up in the community in these meetings.

"I was trying to find out what her goals were for herself,… trying to get an understanding of how her condition affected her, and also about her previous condition as well, how that had affected her, too.…so it was getting her to become independent, get her confidence, and start walking and mobilizing and doing normal things.…presented her to the MDT, the concerns and her goals and what we had talked about with the patient about her goals and where she

wanted her care to go. From that, we identified different areas to refer to different services, like social support, to stroke organization for funding." - Claudia's KW's interview.

MDT goal discussions were fed back to the patient and goals reviewed in all cases except one where the patient was discharged early and clinical need took precedence over research. In other cases professionals spent time with patients to share information. Moreover, in the goal review meeting information related to the logistics of discharge and discharge destination was discussed by the keyworker.

"KW said that MDT had discussed that he could achieve all his goals. He could do everything except driving which will be after 6 weeks. Wife asked about his discharge plans…." Field notes from Jonny's meeting with KW.

The proposed step in the T-PEGS where the keyworker could discuss MDT feedback on the patient's goals during the ward-rounds was found not to fit in the current system since the ward-rounds took place before the MDT meeting. Alternative strategies were planned to enable this strategy by a keen keyworker.

"KW said that since Monday MDT takes place after ward-rounds we can possibly get patient's input on the Tuesday's ward round." Patsy's KW in a meeting with the researcher.

Yet, this was not feasible since not all keyworkers were present on the ward during the ward-rounds, and these did not take place at a set time in some cases, limiting the participation of other team members. However, though the focus was mainly on medical issues during ward-

rounds, in some cases, the psychosocial issues and patient dilemmas revealed during the goal-setting process resulted in a wider focus on psychosocial issues.

> *"Doctor asked patient why he was not happy to go to rehab hospital as KW had informed him…. Doctor asked the team if he did not want rehab hospital, how long it will take for Early Supported Discharge." Field notes from Mohammad's WR.*

6.2.3.2 Practicality

Practical issues were highlighted during the execution of the various steps, in trying to fit the process within the routine system. In one case where the keyworker was not on duty on the MDT meeting day, she had to hand over her case to another professional to be discussed within the MDT meeting. Though the delegation of her responsibility was innovative, another keyworker found the handover was limited and ineffective.

> *"If I'm working just three days obviously if I'm not with J [patient], I had to pass it over to N … (Jonny's KW); I think that's it, isn't it? If the MDT falls on your day off… (Claudia's KW); It's okay to read out what they have written, but then when the rest of the team then ask you a question about it you don't know any more than what's written down…(Mohammad's KW)…." SFG.*

Thus duty rotas, interruptions during meetings, professional roles with multiple demands, and unpredictable work schedules that did not coincide with patient schedules were suggested as practical issues.

Yet another issue that occurred in this handover was that the completed goal-setting document was misplaced by the keyworker. This had a knock-on effect on the recall of the patient about his discussions with his keyworker.

> *"Perhaps if she has it documented it would be good, which is what I should have done as well." Jonny's interview.*

Moreover, short stays and lack of private space for discussions did not facilitate bonding or deeper conversations between patient and keyworker as identified by Patsy. Another patient-identified practical issue with the T-PEGS was that the frequent discussions about setting goals were a bit tiring.

> *"Maybe instead of everyday, once a week cause it can be a bit, it's the same old …it can get a bit monotonous cause you are saying the same thing every day…" Carson's interview.*

Interestingly, this patient had also reported being bored on the ward. Despite his boredom if he found participation to be intense this indicates that the frequency of meetings needs to be tailored to patients' preferred level of involvement.

Most importantly a facilitator to roll out the process was a key resource in all of the cases. The facilitator linked the keyworker to the patient, reviewed the steps in the process with the keyworker and was available for guidance at various steps of the process if required. The staff coordinator who was originally allocated the role of the facilitator was unavailable to carry out these responsibilities due to the demands of her work.

6.2.3.3 Demand and acceptability

An understanding of the demand for the new process would indicate potential use of the T-PEGS in future. Satisfaction and appreciation for the process would indicate whether this resource was accepted by the end users. The actual use of the T-PEGS could indicate whether it was suitable for the participants and whether stakeholders would be able to use it in future. Hence these attributes for acceptability and demand were examined within the data and are discussed below.

Demand for the process was suggested from the staff, based on the organisational motives to improve the current process and shift towards a patient-centred model. Moreover professionals suggested that the T-PEGS facilitated allocation of time to think of patient goals thereby improving the conciseness and specificity of goals.

> *"To create a consistency to goal setting across patients to ensure that I consistently offered that opportunity to all (Patsy's KW) …individualising yes…More patient centred? Well, moving away from the medical model, which is what you said, isn't it? (Carson's KW)...." SFG.*

> *That [MDT] worked very well, because you've got the goal broken down to just two or three goals, quite concise, quite specific, and then you've got people to feedback… I suppose the difference is the time that you give somebody to focus on goals, because normally you might do that as part of another assessment." Patsy's KW's interview.*

Acceptability from the patients was inferred from the fact that all five patients within this study had been pro-active in filling in the document before the scheduled goal-setting meeting with the keyworker. They set goals for themselves specific to their situation. Thus they were prepared for goal-discussion and actively participated in these discussions with the keyworker. In two of the cases, families also opted to actively participate in the meetings.

> *"(in the first meeting) Patient started filling the forms before we left the room … (in the second meeting) KW went through each question and repeatedly asked if there was any more to add. Patient added a few more points…. (in the third meeting) She asked again if he needed anything… He said his food was dropping everywhere since he was not able to hold the plate with the other hand. She said that will be a goal to become independent with eating and will ask the OTs about aids." Field notes from Carson's meeting with KW.*

Acceptability from the professional quarter was evidenced by their willingness to encourage, appreciate, support and reassure not just the patient but carers as well in some cases. Professionals even sign-posted sources of information when they were not aware of certain information.

> *"KW prompted if they had any queries to write them down in the space in the work book and she would come back on Wednesday to answer them… KW said (to patient's wife) that he was good and able to chat for himself… Wife's question on whether she can go back to work KW said he will be independent and if he needs her he can call her and so she can go to work." Field notes from Jonny's meeting with KW.*

"I think my patient found it quite reassuring, you know, that there was further support in the community for the future" Claudia's KW in SFG.

Keyworkers were seen to extend their responsibility beyond the scope of the T-PEGS. They set up strategies for extension of PCGS such as a review of goals in stroke outpatient clinic and were more flexible in their planning.

"Follow up telephone call to review GS process following discharge …" Patsy's Notes

Moreover the process was seen to be attractive to professionals due to gaining an awareness of challenges within the routine goal-setting process, a sense of empowerment, a sense of satisfaction and confidence derived from their roles.

"at the time it made us reflect on the way we did those processes (Patsy's KW)… it makes you realise what you should be doing, and then obviously implementing it because you keep remembering it and doing the processes…(Carson's KW.)" SFG.

"It's the opportunity to take me away from just nursing and care as well, isn't it? Do you know what I mean, to concentrate on actually that person has, but obviously we're not the ones that are setting those goals so it's nice to have…It's nice to have goals, to be more involved in it I think, definitely." Jonny's KW in SFG

"the training kind of brought that to light and gave you a bit of confidence in your own approach (Patsy's KW)… having just that time to sit down and kind

of talk about what they wanted, and to feel like that we understood them I think and understood what they wanted to do (Jonny's KW)." SFG.

Wider acceptability was suggested by staff's views regarding their team leaders' satisfaction with the process. Moreover, it was observed that a professional, who was not a keyworker, facilitated strategies for goal achievement and review of goals.

"I think the consultants are quite interested in having keyworkers and getting the therapist to talk about the people, the patients in the MDT and things like that rather than it coming straight from the doctor's point of view" Claudia's KW in SFG.

"Clinical lead said we might need to put him on stroke clinic list as he needed follow up for his goals… Consultant said … it was fine to put him on the list." Field notes from Jonny's MDTM.

Despite the above indications for acceptability, there were some issues regarding appropriateness. One keyworker perceived that goals set using the T-PEGS were broad and the team was not supportive to refine these broad goals to be more concrete and realistic.

"I think perhaps the physiotherapist felt that was a bit either unrealistic or very, very broad. So, I asked if that was his goal, how can we make our goals fit into that and how can we relate to that? ... It would have helped us in the MDT if we could have broken it down a little bit and also helped him in terms of his expectations..." Carson's KW's interview

6.2.3.4 Integration within existing practice

A discussion on how well the T-PEGS fitted into existing practice will indicate whether it will be a considered as an added burden and discarded or whether it will be sustainable for the future. Therefore factors relevant to integration within existing practice are discussed below.

The routine practice of profession-specific assessments, followed up with profession-specific goal-setting in the MDT meeting existed alongside this patient-centred approach. There was a tendency to slip back to profession-specific goal discussion in some of the keyworkers. Hence this process was perceived as an additional process which took time away from their normal responsibilities. These attitudes of certain staff point to some resistance to applying the T-PEGS.

> *"KW (who is a physiotherapist) said Mohammad was in goal-setting study. Read details about him. KW expressed one of his goals was that he wanted to have normal diet…Doctor asked what his goals were for this week. KW said walk with aid." Field notes from Mohammad's MDTM.*

It is possible that this resistance to integration was due to professional beliefs, motives and experience. For example beliefs about patient's recovery profile, functional ability and patient's safety were the common goal determinants; these still guided the goals set by most professionals involved in this study more than the patient's expectations.

> *"It's slightly different when it comes to dysphagia, because there is a safety aspect, and if he had been presenting with swallowing problems, whether he*

was concerned about them or not, we have to focus on that….." Carson's KW's interview.

A new document which involved collaborative and comprehensive input from the different disciplines for assessment and goal-setting had been introduced in this setting for routine practice. However use of this document was still ineffective, not fully integrated within the system as only the therapists inputted into this document and did not complete the goal-planning sections of this document.

"Document has scope for (Leisure/hobbies/health/cultural/religious)/Social support (lives with, support network/previous Package of care/privately funded support)
This document showed patient was thrombolysed on 19.03.14.Continence not done due to thrombolysis protocol/cognition completed/rest of the assessment left blank." Patsy's document.

It is possible that the resistance to integration observed from some keyworkers was due to their belief that routine practices were adequate. However this belief had been considered as a perceptual gap (i.e. what they believed and what actually happened) in Study one.

"I think in regard to how we work, …we would discuss them potentially twice within the first week…probably the goals or something we need to check or discuss, then we discuss with the therapists very, very regularly…the smaller goals we have achieved stuff… then we liaise with the rest of the team straightaway for them to tap into as well, and we might change goals." - Mohammad's KW's interview.

Nonetheless professionals' motives for patient-centred practice and experience in goal-setting seemed to help most keyworkers to adapt the process to suit their communication styles and confidence. Professionals were fairly independent in applying the process with patients.

> *"I've used the process in the past and found it does guide your clinical reasoning quite well…. Yes, so it's opportunities to improve?" Patsy's KW's interview*

> *"like we all set aside time to be doing this because it was for the study (Mohammad's KW)…I'm not sure it's fully found its way into the processes at this stage. I'm not sure it has really changed the whole culture, but at the time it made us reflect on the way we did those processes (Patsy's KW)."SFG.*

Potential challenges suggested by keyworkers for long term application of T-PEGS were that, evolving recovery profile leads to change in goals; it was burdensome to re-negotiate goals with patients. Time, logistics of running the process with more patients was considered to be potential challenges even though keyworkers perceived that it did not take long for patients to complete the workbook in this study.

> *"if you set goals with them within the first couple of days that they're there, often something happens and changes things and that is quite hard to backtrack, so they might evolve their stroke, or extend their stroke, or have another stroke, or get unwell, …" Jonny's KW's interview.*

> *"I think,…if there were numerous physios or numerous occupational therapists or speech therapists that all have patients, the time kind of everyone*

coming to that meeting to feedback one patient each, I don't know how it would work.(Jonny's KW)." SFG.

Professionals also pre-empted issues such as organisational challenges with regard to the continuity of the process in the subacute setting. Further, the suitability of process for patients with communication problems, poor prognosis and complex issues was questioned.

"I don't really think our links with that rehab setting are as good as they should be in terms of handover information and things like that, so then he has to rebuild and restart all that again three days later (Mohammad's KW)….Complex and the people that don't have a voice… it didn't really start to even tackle that problem (Patsy's KW)." SFG.

Challenges, not specific to participants of study but in general, for the application of the T-PEGS suggested by professionals were similar to those identified pre-application. These were based on patient factors (diagnosis, limited insight and unclear prognosis), system factors (short stay, acute setting, family involvement) and professional factors (workload, limitations in knowledge).

Total time for the various meetings between the keyworker and patient ranged from 15 minutes to 67 minutes in different cases. The MDT meeting which included reporting of goals by keyworkers as a part of the T-PEGS lasted from 6 minutes to 12 minutes for different patients. Though the time taken for discussing each case in routine MTD meeting in Study one was similar to this time period, staff focus group data suggests that professionals felt discussion of each case was time consuming. Hence, logistically, rolling out the process for

an entire ward would require planning and redistribution of workload to accommodate the time costs of a patient-centred process.

The key findings from this study are discussed briefly in the section 6.3 below whereas the wider issues and implications for research and practice are discussed in Chapter seven.

6.3 Discussion

6.3.1 Recruitment challenges and generalisability

Due to the inclusion criteria that patients should not have cognitive issues or major communication problems or serious illnesses, half of the patients who were screened were ruled out. On the other hand, since the T-PEGS required a few days of hospitalisation, patients who had very mild strokes or those who did not need hospitalisation (one third) were ruled out. Thus the sample for this study was not representative of the patient population on the ward. Due to the logistics of matching professionals to patients with relevant issues, to act as the keyworker, a few more patients who were eligible were not approached. Thus the narrow inclusion criteria, and pragmatic issues, made recruitment challenging. These factors further limit generalisability of findings which is discussed in detail in the discussion chapter.

6.3.2 Time as a challenge to practice improvement

Finding time to get to know patients and involve them in a patient-centred process was a main challenge voiced by professionals prior to applying PCGS and after its application. Time has been stated as the main resource challenge in other studies that involved patients (Monaghan *et al.*, 2005). Yet, in another study, therapists who involved patients better, took on average

20 minutes less than those who did not (Northen *et al.*, 1995). It is possible that this variation in timing is because a new process was trialled in the former study whilst routine practice was audited in the latter where there were no additional meetings or forms to fill in. However, considering the potential gain in participation and commitment to change, the extra time spent on using new forms or additional meetings could be considered a better use of time (Duff, 2009). It is suggested that the increased time that therapists use for focusing on administrative and non-therapeutic activities in the UK compared to stroke units in Belgium (Putman *et al.*, 2006) could be diverted towards such patient-centred processes.

6.3.3 Feasibility issues

The strategy within the T-PEGS to provide patients an opportunity to discuss goals with different professionals during ward-rounds was not feasible, though it has been previously evidenced to improve patient involvement (McGrath and Adams, 1999). This was perhaps due to professionals' concerns regarding discussing sensitive items such as their investigations and treatment, and the increased time involved if patients started discussing issues (Laws and Amato, 2010). Laws and Amato (2010), who evaluated nurses' change-of-shift reporting next to the patient's bed found that this process provided patients an opportunity to discuss their plan of care. However, resistance to change amongst staff due to their perceptions about confidentiality and time consumption had to be overcome. Laws and Amato also reported that the enthusiastic support of manager and director during implementation was a key factor in overcoming resistance. As regards the present study, the fact that the researcher was an outsider (not a trust employee) meant that there was no noticeable impetus from the trust leadership. In order to improve fidelity (i.e. to ensure the proposed steps are actually followed) future applications of the PCGS process should

endeavour to establish the support of local leaders to gain a top-down facilitation of change along with the change in individuals' behaviour. Previously, leaders who were committed, able to effectively communicate and drive patient-centred strategies were identified to be the key reason for success in eight healthcare organisations that were recognised as exemplars in patient-centred care across the US (Luxford, Safran and Delbanco, 2011)

Moreover, it was not feasible for the stroke coordinator to take up the responsibility of introducing the goal-setting process to patients and co-ordinating keyworkers' responsibilities (refer section 6.3.2). This step was proposed to give ownership of the application and the process, in case of long-term uptake of the process. However, it was found that the responsibilities of stroke coordinators away from the ward were not conducive to them taking up this additional responsibility. Staff shortages and multiple demands on individual professionals have been problematic elsewhere (Elsworth *et al.*, 1999; Holliday, Ballinger and Playford, 2007). In hindsight, within a complex system such as a stroke unit, targeting alteration in one person's responsibility was not an effective strategy in Study two. Rather the focus should have been maintained on the entire group of professionals (Grol *et al.*, 2007).

There was limited time for the review of goal-setting to take place in one particular patient who was discharged earlier than expected. Clinical care took precedence over research in this case within the limited time available. This was an ethical decision which inevitably overruled the research design. Additionally, in one case, time lapse between the application and the interview of the patient made it difficult for the patient to recollect details of the process. Patient needed time to settle in the community before being ready for the interview in this case. Thus logistical issues in the real world had partial influence on data collection and

findings. However, flexibility in the use of the T-PEGS and in methodological aspects of the study was helpful to complete study without compromising on the ethics.

6.4 Summary and conclusion

This study was carried out to evaluate whether the application of the T-PEGS in a small number of patients improved aspects of patient-centredness in goal-setting, the pragmatic aspects of feasibility of application and the perceived outcomes (effects) of the T-PEGS. It was found that there were observable improvements in the adoption of various components of the bio-psychosocial, empowerment and sharing responsibility dimensions. Most importantly the therapeutic relationship was observed to have markedly improved between patient and professionals in this study compared to the observations in Study one. Several challenges were perceived by the clinicians when applying the T-PEGS within the setting. Clinicians also suggested challenges for future application on a wider scale. Nonetheless, the T-PEGS was applied mostly as intended, mainly due to the facilitatory attributes of the staff participants. The perceived benefits due to the T-PEGS focused mainly on psychological benefits (e.g. confidence, reduced stress, satisfaction etc.), for both patients and professionals. Participants did not suggest potential functional or economic improvements as result of applying PCGS. Therefore, weighing up the feasibility issues observed during this study and the overall methodological limitations, recommendations for practice and research will be made in Chapter seven.

CHAPTER 7

DISCUSSION AND CONCLUSION

7.0 Overview of chapter

This chapter will summarise the findings from the different studies in this research and discuss key findings within the context of the wider literature and healthcare practice. It will also discuss limitations within the research methods and findings critically, and suggest implications for future wider practice, education and research.

7.1 Summary of findings: Practice of PCGS and its effects

The literature review revealed that practitioners and the healthcare systems in wider practice adopted the principles of patient centredness within goal-setting to a limited extent. Professionals mostly attributed this limited PCGS to the patients' ability to communicate, their level of cognitive function and their uncertain prognosis, while they themselves were trying to manage multiple demands within a resource-strained system. Patients seemed to agree partially; particularly with their unpreparedness and that their illness was limiting their participation in goal-setting. However, a key contributing factor identified was the lack of structured processes, built on empirical evidence, that facilitated patient involvement to implement PCGS in practice (Rosewilliam, Roskell and Pandyan, 2011). Thus further work towards supporting practitioners to become more patient-centred when setting goals with patients was indicated. Moreover, the review had also identified that PCGS could potentially improve psychological aspects of participation and satisfaction and result in better function

(despite its limited adoption) which was an additional motivation to pursue this developmental work.

In the exploratory study of local practice (Study one), patients reported non-collaboration and disempowerment within goal-setting. This corresponded to observations regarding the lack of a therapeutic relationship with professionals, evidenced by their frustration and lack of trust. Perhaps, due to this dysfunctional relationship with professionals, patients held attitudes (e.g. not to bother staff) and beliefs such as, staff were unapproachable, which restricted them from coming forward and collaboratively setting goals with professionals. The key effect of this non-collaboration was that the patients' psychosocial needs were not often considered. Further the system factors of restricted resources, bureaucracy, and the perceived hierarchy, along with professionals reporting that they had limitations in knowledge about disease prognosis, goal-setting and application of patient-centredness, indicated disempowerment of staff. Nevertheless, certain professionals were observed to have perceptual gaps i.e. they perceived that they were already patient-centred in their practice and were also authoritarian in certain decision-making situations. This manner could have become ingrained in the personality of the staff since they had to make vital decisions regarding medical stability in acute contexts (Bendz, 2000). Thus, the imbalance in power and knowledge between patients and staff in Study one mirrored the review's findings regarding a need to support patients and professionals.

Strategies to support the development of PCGS identified from the literature included better communication, empowering patients through providing information and opportunities, professional training, and structures to facilitate PCGS. These strategies were in line with the suggestions of patients and professionals in Study one, and appropriate for the challenges

identified in local practice. Patients suggested building therapeutic relationships by encouraging one-to-one contact, psychological support, improved communication and involvement in goal-setting. Professionals on the other hand required structural support, and empowerment through education and training to adopt PCGS. These strategies identified from Study one were integrated with evidence from literature to build a resource (T-PEGS) to improve PCGS in practice. Pure evidence-based practice might suggest a course of action a patient does not wish; likewise there are some areas which might be important for the patient but are difficult to establish with evidence-based interventions (Cott, 2004). Therefore a middle ground for the integration of pragmatic, locally feasible solutions with evidence was adopted to build the T-PEGS.

Study two which was designed to evaluate the feasibility, appropriateness and effects of applying the T-PEGS in practice suggested improvements in rapport between the patients and professionals indicating a better therapeutic relationship. Further, patients stated receiving better information and felt empowered to participate and problem-solve. Vitally, patients' psychosocial needs were recorded along with interventions for these needs. Professionals found that the process gave them awareness of their behaviour, helped them identify holistic needs and gave patients the opportunity to be involved in goal-setting. However, certain aspects had scope for improvement, such as the exploration of patients' subjective experience of illness, future health promotion and encouraging self-efficacy and hope.

With regard to feasibility of application of the T-PEGS in this setting, execution of strategies to involve the MDT during ward-rounds and the role of the stroke coordinator as a facilitator were not feasible in this setting. Therefore, the researcher had to play the role of the facilitator which was key to administering the T-PEGS. Practical issues such as a keyworker's absence

during an MDT meeting and misplaced documents were observed. Nevertheless, acceptance of this process was evident as patients and professionals performed their roles and responsibilities effectively, perceived a sense of empowerment in their roles and also had some support from team leaders for rolling out the T-PEGS. Yet, integration within practice was suggested by professionals to be incomplete since they had to take time away from their pre-existing routines to apply the T-PEGS. Some resistance to change was observed in professionals. The findings from these studies will be discussed in the following section within the background of the existing literature.

7.2 Relevance of study

The national guidelines for stroke care, considering the significance of goal-setting, have moved the deadline for setting goals from point of discharge to within five days of admission (ISWP, 2012). Despite being regularly monitored by the National Sentinel Audit, (NSA), whether goal-setting practice meets the standards is a major question. For example, the stroke unit studied in this research had scored 100% on the goal-setting targets in NSA 2010 (ISWP, 2011). However, the Study one following this audit had revealed that patient goals were not recorded in documents on this unit. So what had been audited were the goals of professionals rather than patients' goals, contrary to the requirement for PCGS (ISWP, 2012). This discrepancy had several implications. Firstly, the need to improve the quality of goal-setting was crucial. Secondly, staff had professional pride that they were performing well and did not need to change their practice of goal-setting, making change more challenging (Schein, 1996). Most importantly, professionals might have been working towards audited targets, similar to the policy pressures identified in the Francis report (2013), by compromising on the quality of

the process. For example, patient involvement in goal-setting that took time was avoided; instead it was reportedly done by therapists during therapy sessions. Thus the intention of this work to explore and develop goal-setting processes was justified. What follows is the grounding of the approach and the findings of this work in wider practice.

7.2.1 Reasoning behind adoption of an empowering approach within the study

Routine goal-setting processes must involve patients (ISWP, 2012), because involvement could improve self-efficacy through feedback, encouragement and information provision (Bandura, 1991). Collaboration could influence the development of goal intentions by influencing the patient's perception of risk, expectation of outcome and self-efficacy. All these aspects affect the patients' motivation to pursue goals (Schwarzer, 1992). Since PCGS involves a motivational phase and a volitional phase where action planning occurs, it could improve self-efficacy, and develop goal intentions and action plans that are personally relevant and therefore motivate and direct patients' attention and effort towards these goals (Locke, 1996). However, goal-setting in this study setting was found to be owned by the professionals, was implicit and not recognised by patients, similar to findings elsewhere in UK practice (Holliday, Antoun and Playford, 2005). Thus patients were disempowered by not providing them opportunities to collaborate. Therefore, an empathetic and empowering approach was adopted for the further design of the subsequent phases of the research.

As a first step, patients were informed, educated and provided opportunities to participate within a more patient-centred system following suggestions from patients in Study one and elsewhere (Cott, 2004). Study two within the present research is a step towards empowering professionals by training them to be patient-centred. Thus the work was an overall attempt to

build processes to encourage 'productive interaction between an informed, active patient and proactive and trained professionals' (Wagner *et al.*, 2001, p 68).

7.2.2 Professionals' dilemmas and communication skills

Professionals in Study one suggested it was important to protect patients' emotional wellbeing by not giving hopes of recovery. This concern potentially caused their dilemma regarding whether they were giving false hope to the patient when they set high level goals, especially when they did not believe the recovery potential was good for the patient (Parry, 2004). Elsewhere, professionals either avoided goal-setting (Lawler *et al.*, 1999) or provided goals they thought were achievable (Parry, 2004) and fitted in the system (Levack *et al.*, 2011). This is ostensibly paternalistic and resulted in one-way communication (telling patients rather than asking), and reflects a situation where the professionals lack communication skills, especially competent listening skills (Parry, 2004; Almborg *et al.*, 2008).

Communication, when problematic, was perceived as disrespectful; it affected rapport and appeared to cause a breakdown of the therapeutic relationship. Patients had suggested they be treated with respect, be listened to and have access to information from approachable and friendly professionals, similar to patients studied in the US (Nordehn, Meredith and Bye, 2006). Some patients even expressed anger due to the lack of communication just as patients elsewhere (Alaszewski, Alaszewski and Potter, 2004). Establishing an effective communication channel would take time amidst the varied responsibilities that professionals have (Playford *et al.*, 2000). Hence the need for an effective channel was fulfilled by the role of the keyworker identified from the literature (Holliday *et al.*, 2007). Subsequently, in Study two, patients reported that they had received adequate information and were consulted on their needs through this channel. However, the role was suggested to be ineffective if

keyworkers lacked commitment or a certain level of communication skills (Van De Weyer Ballinger and Playford, 2010).

In this study and elsewhere, nurses, due to their continual contact with patients, have been suggested as key communication channels and a resource to identify patients' problems and needs (Young and Tolentino, 2009). Nevertheless, Study one had revealed that nurses were disempowered to follow patient-centred practices such as giving information about recovery due to the perceived hierarchy. Nurses were neither involved in the goal discussions during ward-rounds nor in the MDT meeting and did not set rehabilitation goals (c.f. Wressle, Oberg and Henriksson, 1999; Bendz, 2000; Ferguson, Worrall and Sherratt, 2009). It is possible that traditional responsibilities and routines of care for nurses did not enable their potential to contribute to goal-setting process. The limited contribution of nurses to this key process is surprising since the theory related to goal-attainment in nursing is widely advocated to underpin nursing practice (King, 1997). This theory suggests that good communication skills must be employed to establish goals and be followed up with transactions that will achieve goal-attainment. It was clear that nursing practice locally was not founded on this framework (reasons for which were not explored within this work). However, the nurse who acted as keyworker during the application of PCGS in Study two suggested that it was an opportunity for nurses to be involved in roles different to routine healthcare, and was thus an example of professional empowerment per se.

7.2.3 Team functioning

This study identified challenges in team functioning such as hierarchy, bureaucracy and resource limitations. Hierarchy shaped the discussion, with doctors leading the discussions in the MDT meeting in Study one prior to the introduction of keyworker role (c.f., Ferguson,

Worrall and Sherratt, 2009). However, Study two identified that medical personnel were both willing to let other professionals lead and looked for acceptance from the team to ratify rehabilitation decisions. It is possible that the medical authority within the team is a perception held by therapists and nurses in this setting and elsewhere (Baxter and Brumfitt, 2008). Attempts should be made to train the team members in leadership skills and provide opportunities to share responsibilities of the team.

Team level function was affected by miscommunication between team members regarding patients' needs in Study one. Goal discussion did not take place in MDT meetings though they would have been ideal to communicate goals to team members. Moreover, goal-negotiation between members of the MDT in these meetings leading to collaborative goal-agreement would have supported setting holistic goals rather than uni-professional goals. Instead communication between professionals happened in informal situations that could be described as 'fringe meetings' (c.f. Suddick and De Souza, 2006) where decisions were made (Baxter and Brumfitt, 2008; Ferguson, Worrall and Sherratt, 2009). Therefore, there was a need for more effective use of processes such as the weekly MDT meetings (Strasser *et al.*, 2005). However revamping the goal-setting process might not be effective without the collaborative efforts of the members involved in it (Elsworth *et al.*, 1999). Collaborative team working has previously been shown to be a predictor of effective care; therefore efforts need to be taken to improve team cohesiveness which include having common goals, sharing information and experiences, having defined roles and training to improve team-working skills (Grol *et al.*, 2007).

Inter-professional care which is integral to PCGS was reported to have improved by professionals who underwent inter-professional training (McKellar *et al.*, 2011). Their

training had included case examples, experiential learning and reflections. Hence a similar approach within Study two involving inter-professional training methods was adopted to enhance communication, collaboration and understanding of others' professional roles - needs that were identified within this setting. Consequently, collaborative efforts were observed during the process of application of the T-PEGS and for setting up interventions relevant to identified goals.

Despite some observations of aspects of team cohesion in Study two, there was one case in which a keyworker felt that she was not supported by the team to link the broad generic goal voiced by her patient to relevant therapy goals. This could be attributed to professionals trying to protect their professional identity and practice, perhaps an outcome of uni-professional training and regulation. Instead professional training that involves inter-disciplinary working wherein goal-setting is done at participatory levels and shared by all the team members (Suddick and De Souza, 2006) is clearly required for PCGS.

7.2.4 Patients' emotions as barrier to participation

Prior to this study it was considered that PCGS which involved patients was a challenge especially in acute care (only 5 studies were identified in the review), since patients were still trying to cope and were adjusting emotionally to the sudden onset of stroke (Playford *et al.*, 2000). However, the current study's findings provided an alternative view of the potential to participate in goal-setting during the acute stage. Patients in Study two actively became involved in goal-setting when given the opportunity to do so, clearly demonstrating good motivation. Following the application of the T-PEGS, goals and interventions for emotional and social issues were formulated. Moreover, there was an improved therapeutic relationship wherein patients trusted professionals and felt respected and cared for. Patients felt reassured,

less stressed and more supported for emotional issues. These attributes were vital to empower patients leading to their involvement in goal-setting. Thus, it can be argued that a patient-centred process, through reducing the emotional issues for patients and establishing a better rapport, improved patient involvement in goal-setting. Thus PCGS could be a means to tackling emotional issues that disempower participation, rather than emotional issues inhibiting adoption of PCGS.

On that subject of alleviating emotional issues, patients in other studies have reported that, emotions such as fear, sadness, frustration and confusion had improved following their involvement in goal-setting (McGrath and Adams, 1999). Depression scores had reduced by clinically significant levels in patients in McGrath and Adams' (1999) study. With an estimated prevalence of depression in approximately 33% of stroke survivors (Hackett *et al.*, 2005), and depression being identified as being related to participatory limitations and lower health related quality of life (Skidmore *et al.*, 2010; Andrenelli *et al.*, 2015), the evidence that PCGS could help reduce depression looks promising. Moreover with a possibility to have improved functional outcomes following recovery from depression (Chemerinski, Robinson and Kosier, 2001), it is pertinent that the role of PCGS be further evaluated in this aspect.

7.2.5 Carer involvement

Carer involvement in making decisions has been viewed as problematic for a patient-centred approach in the literature. Professionals sometimes employ family members as proxy goal-setters but warn that goals might not always be in the best interests of the patient (Levack *et al.*, 2009). Professionals in Study one had indicated that families were sometimes considered as demanding. Despite this belief, most professionals in Study one said that they collected information about patients from family members. Simultaneously, most patients in Study one

had indicated that families acted as communication channels and as advocates similar to patients in Huby *et al.*, (2004) study. Family or other social support has previously been identified to enable patients' involvement in planning and decision-making (Roberts, 2002). Subsequently, during the application of the PCGS in Study two it was observed that four out of five patients had family involvement in the process. Families acted as communication channels and supported the patients during the discussions about their goals. Thus, while the choice of family involvement is left with the patient in a patient-centred process, the MDT should consider the vulnerability of the patient against the family dynamics while establishing goals for a patient (Brashler, 2006).

7.3 Limitations of the research

Rigour and reflexivity were integral to the trustworthiness of the findings from this work, helping to improve the readers' confidence in the knowledge claims made by the researcher (Porter, 2007). Though strategies were adopted to address methodological rigour within the studies' methods, this work is not without limitations. These limitations have been classified as those pertaining to research methodology and those relevant to practice and have been discussed in the following subsections.

7.3.1 Methodological limitations

Generalisability of findings from this work is limited due the small sample sizes and lack of data saturation in the study. Small sample sizes were due to the acute nature of setting, quick turn-around of patients and limited staff numbers. Repeated interviews and larger numbers of interviews that contribute to data saturation were not feasible due to the above reasons. Also

data saturation was not aimed for since the constructs studied (patient-centredness and goals) might be potentially limitless. Also this was a single site study investigating a single modus operandi. Thus the findings have to be interpreted within the limited context.

Generalisability is also limited as the researcher acknowledges that knowledge conceptualised within qualitative research is particular to the group of participants in their specific context.(Grant, 2005); therefore efforts were made to improve transferability for the reader by rich description of the context and participant characteristics in chapters four and six (Krefting, 1991). This could help extrapolation of relevant findings to other contexts. For example the increasing prevalence of long term conditions warrant patient-centred goal-setting process for effective self-management (Coulter, Roberts and Dixon, 2013); there is scope for the flexible use of tools from this resource to be adapted for use with patients with chronic conditions to inform personal and contextualised goals. However the onus of transferability rests on the reader since the researcher cannot make inferences regarding the receiving end (Shenton, 2004).

It is acknowledged that there were possibilities for a 'Hawthorne effect' during observation (Bowling, 1997, p. 137). In order to avoid reactivity of the team members (observer effect) to the presence of the researcher, the researcher introduced the study and stayed on the ward for two months (prolonged engagement) before the data collection and embedded herself within the team (Mulhall, 2003). Prolonged engagement to reduce desirable social responses by respondents could have consequences on the stance of the researcher potentially leading to researcher bias (Krefting, 1991).

The interviews for the exploratory Study one were conducted in the hospital setting which could have inhibited patients discussing their care without reservation. However, the

researcher was an outsider which may have encouraged patients and professionals to speak openly about issues in the service delivery. Prolonged engagement with the professionals within this setting also helped build the rapport required to enable open discussions in individual interviews. However, it was noticed that team cohesion and defensive attitudes came across when professionals came together for the focus groups, when they voiced beliefs that they were already patient-centred. This professional perception is not uncommon (Wottrich *et al.*, 2004) and is potentially due to their lack of understanding of the full extent of patient-centredness (Northen *et al.*, 1995; Baker *et al.*, 2001).

The interviews in the study were one time interviews that generated momentary data reflecting practice. With regard to the timing of interviews in the second study, those arranged after patient discharge resulted in loss of information due to problems with recall.

Member checking of research findings are supposedly a strategy to cross check if people who share the experience recognise the description. Nevertheless, patient participants in their acute stage of their illness might not consider this role of research validator as a priority. Hence member checking was not done. Instead presentations to ward staff, before setting up the study and following data analysis, were done partially for member checking also to help shape the design of study (Shenton, 2004). Staff acknowledged that the information presented reflected their views improving credibility (Kidd and Parshall, 2000). Similarly peer evaluation at different points of the research process (panel interviews annually), getting a clinical perspective from the second analyst who was a clinician and feedback from journal reviewers helped strengthened the study's design; it is argued that some reviewers do not have the expertise or same level of involvement in the research to help strengthen it (Smith, 2006).

Prevalence of patient-centredness in goal-setting was assessed in this study using a framework that was based on a breakdown of the concept. The framework developed for this particular study has its advantages and disadvantages. The specification of components of PCGS within the framework enabled closer evaluation and identification of the individual aspects within practice. However, such an approach also fragments the holistic concept and thus, at times, looking at individual aspects in practice could be misleading of the total practice. For example in Study one, looking at the 'biological' aspects (one component of the concept) was observed to be adopted to a large extent. Looking at this aspect in isolation can be misinterpreted as practice being bio-medical; whereas considering other partially adopted aspects such as awareness of emotions and sensitivity to contexts indicate practice was not entirely bio-medical. Hence a balanced and holistic view of the components adopted is required to undertake unbiased assessment of practice using this framework. Moreover, the reliability of using the framework has not been tested. Nevertheless, future work should involve testing this framework and further developing it as a tool such as a questionnaire to evaluate PCGS in practice.

As this was doctoral research most of the data collection, analysis and interpretation was done by the researcher potentially leading to researcher bias. The findings could have been influenced by the researcher's background, culture, education, beliefs and experiences. However, efforts were made at every stage possible to have a second analyst and interpreter to help reduce researcher bias. Further, regular debriefing in supervisory and team meetings also helped the researcher to take a more neutral stance especially during interpretation and deriving of themes.

7.3.2. Limitations relevant to practice

A serious limitation for generalisability of the findings to routine practice was the inclusion criteria for patients for both the studies, that they must have a diagnosis of a stroke, be medically stable, able to communicate at an understandable level and be cognitively intact. More widely 40% of patients with stroke might have cognitive and communicative problems (Duncan *et al.*, 2005). Since, these people were excluded for this work due to their limited ability to contribute to the research process, this study's findings may not be generalisable to the wider group of patients with stroke. However, without a framework to implement PCGS in patients who are able to contribute effectively, it is hard to conceive processes for patients with additional speech and cognitive difficulties (Kus *et al.*, 2011). Thus this study was a first step towards developing patient-centred processes with patients who can participate, the framework of which can be expanded or modified for patients with cognitive and communicative difficulties.

There are already advances in this direction by Hersh *et al.*, (2012b), who propose a PCGS framework called SMARTER that is based on their research with patients with aphasia. The principles they suggest that make up the acronym SMARTER are: goal-setting should involve **S**haring of information, **M**onitoring of performance with tools specific to patients' goals, **A**ccessibility of information, **R**elevance of goals to daily lives, **T**ransparency of goals and their link to therapy, **E**volving goals in line with recovery and most importantly **R**elationship-centred or rapport (Hersh *et al.*, 2012b). This framework was developed based on a large scale multi-centre study involving patients, carers and speech therapists. The authors suggest many strategies from the wider literature to help application of these principles. Compared to the conceptual framework used for the development of PCGS, the SMARTER framework appears to cover aspects of empowerment and information sharing, personal relevance of

goals, and building a therapeutic relationship. However it has failed to cover the holistic perspective i.e. looking at the holistic needs of patients and what aspects need to be considered for this, perhaps due to its development situated within the single discipline of speech and language therapy. The SMARTER framework provides direction but not specific tools that can be used to test this framework. However, since the principles are broad they can be adapted for a multidisciplinary process taking into consideration the context and dynamics.

Findings from this research might not be relevant to other moderate and severe stroke patients because patient participants might be considered as survivors of mild stroke due to their ability to communicate and understand. However mild stroke is not defined uniformly by researchers (Tellier and Rochette, 2009). Some patients in the study had severe motor and sensory deficits requiring further rehabilitation. Therefore the sample in the study was heterogeneous in the severity, age, gender, social status and ethnicity. Thus the findings may have relevance for a wider group of patients. An additional measure of disability levels would have made this spread clearer.

Patients and professionals volunteered to participate in this research which might indicate higher levels of motivation; this potentially influenced their responses and participation. Further, excluding patients with cognitive and communicative problems and prone to depression could have resulted in further exclusion of patients who were potentially low in motivation (Maclean *et al.*, 2000). However, observations of patient participants in Study one suggested that not all of them were in fact highly motivated since a minority of them left the responsibility of setting goals to professionals (Maitra and Erway, 2006) or withdrew from participation due to emotional issues. However the level of motivation and depression in patients are not certain since these were not formally assessed.

7.4 Strengths of the study

Hitherto, no specific goal-setting processes have existed specific to rehabilitation of patients with stroke especially those encouraging participants' contribution to the process (Kamioka *et al.*, 2009). Methods such as GAS and COPM developed for other conditions have been used increasingly in studies involving stroke patients due to their validity, reliability and responsiveness in elderly and brain damaged patients (Kamioka *et al.*, 2009). However there is a need to consider the element of professional subjectivity in grading goals in goal-attainment, the training required to use these tools, and whether goals that are easy to achieve are set on purpose by professionals using these tools. Most importantly COPM and GAS, which were purported to enable PCGS are not comprehensive enough to enable the various aspects of patient-centredness in goal-setting (Rosewilliam *et al.*, 2015). For example what aspects of therapeutic relationship need to be focused on is not clear within these tools. In contrast, T-PEGS was built on the various aspects of patient-centredness, including the establishment of therapeutic relations, which is vital to patient-centred practice.

Previous studies had mostly considered the perspectives of patients or professionals separately. Yet another peculiar aspect of previous goal-setting studies was that most of them studied the process from the perspective of individual professions rather than of all professions concerned (only 8 MDT studies were identified). However, this study looked at the perspectives of both patients and professionals within the particular context of team functioning. These perspectives were then compared, to study how congruent or divergent they were. This gives a better understanding of the contextual and interactive factors that contribute to limited patient-centredness in this setting. For example patients perceived professionals were projecting a busy-keep-away (unapproachable) front. Examination of the

professionals' perspectives revealed that this could have been a subconscious defence mechanism to mask the fact that they felt disempowered. In addition to contextualising the interpretations, corroboration of ideas presented by the provider and service user to improve validity of findings was also possible (data triangulation).

Researcher credibility for this research was established through the training needs analysis strategy in place for Birmingham graduates which led the researcher to undertake training courses in methods and other skills such as referencing and academic writing for this thesis. Moreover previous experience of working on qualitative studies supports some credibility of the researcher on this project (Patton, 2015, p.731). Prior experience of conducting qualitative interviews for other studies (Rosewilliam *et al.*, 2011) helped the researcher to be aware of issues such as bias in asking leading questions, diversion from topic and time constraints (Grbich, 1999, p. 86). One could argue that the same prior experience or exposure could have influenced the researcher's preconceptions of the process.

Comprehensive data analysis, over cherry-picking of data, was the preferred strategy for analysis of data which resulted in the reporting of not just confirmatory evidence but dis confirmatory evidence with possible explanations (Silverman, 2013, p.291). In that sense a triangulation strategy was helpful to identify deviances from the cumulative evidence (Mathison, 1988). Routinely, triangulation using multiple methods to make up for limitations of one method, or using different sources to corroborate or supplement findings from one source, is adopted to improve credibility. In this work interviews combined with observations and documents analysis were helpful to achieve these purposes. Triangulation is sometimes implied to derive a convergent truth (objective reality) which does not align with the multiple

reality orientation of this research (Silverman, 2006, p.9); rather triangulation was adapted to build stronger evidence for the researcher's interpretation.

Use of an audit trail has been recommended to improve confirmability and due to this work being doctoral research, detailed appendices which link the various stages of data analysis have been presented to enable transparency in the process of deriving inferences (Pawson *et al.*, 2003). Yet an auditor coming from a different background with different perspectives could disagree with the inferences since interpretations are views through the researcher's lens of understanding. Nevertheless, the influences causing researcher bias have been set out in the reflexive account (Preface to research) so that the reader can understand the researcher's philosophy, approach and interpretative stance.

Another strategy, the field journal, documenting researcher's thoughts, decisions and feelings can be used as a tool to isolate researcher biases during data analysis; the journal in this instance was a vent to researcher's feelings. Instead, a more rigorous approach was used, where research supervisors were briefed on researcher's thought process to allow scrutiny of personal influence in these interpretations. Reflexive memoing, an illustration of the thought process of the researcher was done during the process of data analysis. These thoughts were recorded as bullet points at the end of a summary to make it clear that these were interpretations and not data itself. An example of memoing following analysis of one of the cases from Study one has been presented in chapter four (table 4.3). These memos were later drawn on to recapture the evolving thought process that influenced the researcher's interpretations. Thus researcher's interpretations were the result of reflexive analysis and was scrutinised by experts to optimise rigour of this work.

7.5 Wider constraints on patient-centred practice

There are wider reasons why practice might not fully become patient-centred. Competing expectations on the professionals from the team, and organisation and financial constraints have been suggested as causes to deviate from a patient-centred agenda (Gustafsson and McLaughlin, 2009; Barnard, Cruice and Playford, 2010; Levack *et al.*, 2011; Lloyd, Roberts and Freeman, 2014). The culture within the setting was about safety, preventing litigation, confidentiality and data protection regulated by policies and laws. Though non-maleficent, these factors caused professional to adopt paternalistic behaviour (Proot *et al.*, 2000), rather than a partnership in the process. Working within this protective and closed culture perhaps made it difficult for professionals to have a sense of motivation towards patient-centred care (Leach *et al.*, 2010). Further, the question arises whether continual professional dilemmas in practice due to external pressures caused them to retreat into the defensive and reactive culture of the NHS (Dixon-Woods *et al.*, 2013).

Government policies driving organisational targets might have influenced the professionals' behaviours though this was not explicitly examined in this study. For example the policy document Equity and Excellence: Liberating the NHS (DoH, 2010) proposed rating hospitals based on quality standards developed by NICE. Hospitals were audited against targets and the results of inspections influenced the commissioning and payment systems. Though this policy of payment based on performance was set up to ensure quality and value for services, audits of service delivery outcomes can focus on process targets rather than actual quality (an example of this has been previously discussed in section 7.2). What was of concern to this research was whether clinicians compromised on the interactions within the patient-provider relationship in order to achieve the target metrics required for funding.

The Health and Social Care Act 2012 encourages a competitive healthcare system to improve quality of healthcare. According to this act, the 'Monitor' is required to set out requirements based on which procurement of services can occur from different providers. It is questionable whether these requirements will be interpreted and outcomes measured based on quantity rather than quality of the care processes. Moreover, there are also serious concerns that the NHS will lose services and care will be fragmented due to multiple care providers, which may make it harder to be holistic, co-ordinated and patient-centred (Faculty of Public Health, 2012). Moreover this market drive for competitive service provision in healthcare is still debated as there is inadequate evidence that competition improves quality of care in chronic care situations such as stroke. Whether values of patient-centredness survive and flourish in a market driven healthcare system is a question for the future.

When the plans for the NHS for the next five years were unveiled recently, the health secretary for UK called for a move from a target culture to a holistic integrated care that defies bureaucracy to bring power back to patients (The Rt. Hon. Jeremy Hunt, 2015) In his speech he derided the term 'patient-centric' and opted for humanistic care instead. He opted for this shift as according to him patient-centred care referred to "building processes around system targets and system objectives" which dehumanised care. However there are two arguments here. One is that his speech misrepresents the concept of patient-centredness: the other is the assumption that current systems may already be patient-centric and they fail to achieve humanistic care. Rather than dwell on the political ideologies, research and practice should adopt and evaluate principles of patient-centredness that have been established based on empirical enquiry.

Policy pressures and conflicting policies can interfere with the proposed application of PCGS at the point of service delivery. For example given the current health reforms, the reduced social/ welfare budgets, and the proposed efficiency savings of £22 billion (Appleby, Galea and Murray, 2014) the delivery of PCGS process is bound to be affected by further reductions in already tight resources. Moreover a process of goal-setting involving patients which is time consuming can be questioned (Levack *et al.*, 2006b) unless the effects of this process outweigh the cost implications (What works Network, 2014). Hence further research to investigate cost-effectiveness is required.

7.6 Implications for practice

One of the key findings of this work was that patients wanted to gain hope with regard to their recovery. It is possible that professionals expressed concerns about giving patients hope, especially when recovery is slow or unexpected (Cott, 2004) and not wanting to 'dash their hopes' (Lawler *et al.*, 1999, p 406) by agreeing to their high level goals. However, patients in Jones *et al's* study (2008) study discussed hope as a coping mechanism and suggested that maintaining hope could help in the recovery process (Jones, Mandy and Partridge, 2008). Hopeful thinking facilitates motivation (agency) and problem solving (pathways thinking). Moreover hopeful thinking contributes to positive emotions which in turn contribute to goal-directed thoughts through better coping (Snyder, 2002). Therefore based on Snyder's (2002) recommendation, in order to fulfil the need for hope expressed by patients in Study one, professionals should give patients honest feedback on goals that give hope. This could encourage hopeful thinking, and that combined with emotional support could strengthen goal-pursuit.

Loss of control over the situation was identified in the exploratory study when patients felt they were not involved, staff were unapproachable and left with frustration due to not having enough information. Loss of control has been expressed by patients in Bendz's (2003) study due to internal factors such as loss of control over body, mind, energy levels and fear of re-stroking. Locus of control has been identified as an important attribute in the psychology of older adults, influencing what they are willing to work towards and the potential outcomes (Rees, Wilcox and Cuddihy, 2002). Therefore it has been recommended that in a situation without control, at least opportunities that could provide a sense of control should be provided (Guidetti and Tham, 2002). PCGS with opportunities for involvement and information sharing could be a step in this direction (Playford *et al.*, 2000). Enabling autonomy in simple activities in lieu of overprotection, though it involves extra resources, could facilitate a sense of control in hospitalised patients. It is not easy to relinquish control when one is driven by safety culture. However, risk taking and creativity are essential during rehabilitation and these should be encouraged within a safe environment (Brauer, Schmidt and Pearson, 2001).

Patients wanted to regain social identity, similar to the patients in previous studies (Wressle, Oberg and Henriksson, 1999; Reed *et al.*, 2010); hence their goals were high level functional and participatory goals founded on their values and motives. Professionals, rather than ignoring patients' goals as broad, generic and ambiguous, should explore the higher values or motives of the patient in relation to their preferred social identity. Then specific participatory goals or goals that will cater to these motives and values can be set. For example, if a patient's generic goal is to get back to the carer's role due to the value they place on being a caring person, goals that enable opportunities to care for their loved ones must be set (Playford *et al.*, 2000).

There is a moderate level of evidence to support the notion that patients were able to set goals relevant to their daily life when exposed to the context of their own homes (Playford *et al.*, 2000; Boonstra, Wijbrandi and Spikman, 2005). Some patients in this study attest this view; they stated that they could set realistic goals when they can realise their issues in everyday activities better in the context of their own homes. However, this strategy was not feasible within the new process of goal-setting due to the time commitment required from the professionals to undertake home visits along with patients. Practices should consider incorporating home visits, to identify goal priorities which can be set, at least for patients to be discharged home straight from hospital. For others who require further rehabilitation, personalised goals can be constructed from their accounts of their pre-stroke life or by providing opportunities in hospital to try activities relevant to a patient's life e.g. going to the lobby to buy a newspaper.

7.7 Implications for research

PCGS would require its precursor- assessment to be a patient-centred process. However, the assessment process in Study one was identified to be profession-specific and bio-medically oriented (c.f. Bendz, 2000). Nevertheless, Study two had revealed that there was an attempted shift to a more holistic and collaborative assessment document that was being trialled with partial success. This assessment form was based on ICF core categories for stroke encompassing psychological, social and environmental aspects, thus enabling a more individualistic and bio-psychosocial orientation (Albert and Kesselring, 2012). This form was apt because previous studies have shown that the goals of stroke patients were found to be relevant to the ICF categories (Wressle, Oberg and Henriksson, 1999). However, this

assessment form based on ICF has not been evaluated for its efficiency and hence cannot be recommended for wider use. Since an elaborate discussion of ICF is beyond the scope of this work, it is recommended that future work should involve evaluation of the current ICF based assessment form, its link to goal-setting and review of goals in stroke.

An attempt to explore the effects of PCGS has revealed that, in Study two, patients and professionals expressed satisfaction with interaction and information sharing leading to reassurance and reduced stress. Perhaps these positive interactions could help patients to cope better (Carlsson, Moller and Blomstrand, 2004). There is some evidence that patient-centred goals for which specific interventions were delivered resulted in motor recovery and functional gains in few case studies (Deutsch, Maidan and Dickstein, 2012; Broetz and Birbaumer, 2013). Thus the components related to eliciting patient views can improve adherence and components related to activating patient participation can improve outcomes (Michie, Miles and Weinman, 2003). However, whether these psychological effects that indicate a better experience for professionals and patients translate into functional and quality of life outcomes need to be studied further. Patients' well-being, experience and self-management are other outcomes that need further evaluation (Holliday *et al.*, 2007).

The time factor after stroke for PCGS should be considered. Patients with a longer stay had perceived a better participation in planning for care and setting goals during discharge planning (Almborg *et al.*, 2008). Considering that many of the participants in the second study went home following stroke unit care, their needs might have been limited. Future studies need to involve patients with longer stay due to their increased needs and then evaluate whether PCGS is actually effective in this group of patients. Also, whether the application and identification of patient-centred goals resulted in better preparation for life in

the community is not known. So studies that follow up patients in the community are needed to evaluate this aspect.

7.8 Implications for education

Problem orientated goal-setting is the most often used method in neurorehabilitation (Holliday, Antoun and Playford, 2005). This may be due to education, which teaches students to approach management of illness rather than management of a person's health. Professionals set goals that are built on profession-specific assessments whereas patients voice generic life goals (Bendz, 2003). Training should include problem-solving skills for professionals to analyse and separate out aspects of the broad generic goals expressed by patients into sub-goals (Boutin-Lester and Gibson, 2002; Bendz, 2003; Laver *et al.*, 2010) and link these sub-goals to professionals' therapy goals.

Within the education sector, candidates recruited for healthcare professions should be screened for innate qualities of empathy, tolerance, kindness, respect and enthusiasm (NHS – Core values) and be trained to express empathy, be flexible and motivating (DoH, 2013). During training, a patient-centred approached to care and alternate ways of thinking to identify goals that satisfy patients' higher order motives (McGrath and Adams, 1999) should be a part of the training. It was observed that despite applying a patient-centred process in this study, hope and self-efficacy, two major influences on the person's recovery profile (Dixon, Thornton and Young, 2007), were not explored or catered to. Skills for psychological aspects such as instilling hope, enhancing self-efficacy beliefs (with encouragement) and motivational communication should be part of a bio-psychosocially oriented curriculum.

Therapists reported the need for improving their knowledge about theory, evidence and practical skills for goal-setting (Wottrich *et al.*, 2004). However, the patients in this study had expressed trust in the therapists' knowledge to align their goals to their therapy. Therefore therapists have the obligation to update their knowledge and training on latest knowledge around goal-setting using Continuing Professional Development programmes.

7.9 Conclusion

There is increasingly a shift in the patient-provider relationship and the way care is delivered, in that, patients need to be considered as partners in care rather than recipients of care. This shift is fuelled by the evolution in societal norms, and by legal, political and ethical influences on the healthcare delivery. Thus over the past three decades there is rising support for a patient-centred approach in healthcare delivery and the process of goal-setting has been considered a good forum to direct care towards being patient-centred (Playford *et al.*, 2009). This thesis is an attempt to explore the prospects of building better goal-setting processes founded on the patient-centred approach.

One of the key challenges was a lack of defined boundaries to what this approach involved and how it could be operationalised (Leplege *et al.*, 2007). This was the starting point for this work. Key literature in this area was studied along with an exploration of perspectives of patients and professionals locally, using a systematic literature review, multiple qualitative case studies and focus group studies. The findings from these studies helped to determine what was important for a PCGS process. Further, barriers both within the study setting and the wider context were identified. The key finding was the lack of a structured process for PCGS and the need to build a holistic method to empower professionals and patients within

the restrictions of practice. Therefore, following a grasp of the contextual and theoretical knowledge relevant to operationalisation of PCGS a resource (T-PEGS) has been developed. It is a complex intervention involving training and education for professionals, supportive structures that enable patients and professionals to carry out PCGS. The T-PEGS was evaluated on a small scale using multiple qualitative case studies and a focus group. The development of T-PEGS and its parts has been clearly set out for translation to wider practice in this thesis. Thus this work is important as it not only explores the challenges relevant to adopting patient-centredness within goal-setting, but also builds a resource to operationalise PCGS within rehabilitation for patients with stroke; hitherto there were no holistic approaches for the above.

Following the application and evaluation, it was revealed that it is feasible to apply the different tools within T-PEGS with certain limitations. However, there are wider challenges to changing behaviour of patients and professionals that deter them from adopting PCGS in the current NHS culture, e.g. organisational demands. Nevertheless, two aspects of patient-centredness, looking at patients' goals with a bio-psychosocial perspective, and empowering patients through information and opportunities were seen to be better with the application of the T-PEGS. Most importantly the therapeutic relationship was observed to be better leading to improved participation of patients within the process. These findings must be viewed cautiously due to the many limitations discussed above, yet appreciated as the evidence from a focused research built on the entirety of the concept rather than its parts.

The key messages of this work are that patient-centredness in goal-setting can be improved if tools specific to challenges in practice are identified and applied. Creating awareness through education for patients and professionals is a pre-requisite for initiating change in practice. The

observed outcomes of such an approach were improved therapeutic relationships between patients and professionals, establishment of goals for psychosocial needs and perceived psychological benefits expressed as better care experience by patients. With the improvement of healthcare quality relying on 'safety, effectiveness and good patient experience', PCGS is a step in this direction (National Quality Board, 2013). Despite it being a pre-clinical study it has overcome the limitations of translational research in being designed within the clinical setting in which it was intended to be applied. However for a wider generalisability, further evidence of its value to improve aspects of patient-centred care leading to better outcomes and cost efficiency should be collected. This is possible with further research that implements the T-PEGS and evaluates the mechanism and outcomes of this PCGS process in larger studies in varied settings. Thus as a next step, a study involving two groups of patients one receiving routine goal-setting and the other group involved in goal-setting using T-PEGS has been planned in a subacute rehabilitation setting for patients with stroke.

REFERENCES

Ahlsio, B., Britton, M., Murray, V. & Theorell, T. (1984). 'Disablement and quality of life after stroke'. *Stroke,* 15**,** 886-90.

Alaszewski, A., Alaszewski, H. & Potter, J. (2004). 'The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice'. *Disability and Rehabilitation,* 26**,** 1067.

Albert, S. J. & Kesselring, J. (2012). 'Neurorehabilitation of stroke'. *Journal of Neurology,* 259**,** 817-32.

Almborg, A.-H., Ulander, K., Thulin, A. & Berg, S. (2008). 'Patients' perceptions of their participation in discharge planning after acute stroke'. *Journal of Clinical Nursing,* 18**,** 199-209.

Andreassen, S. & Wyller, T. B. (2005). 'Patients' experiences with self-referral to in-patient rehabilitation: A qualitative interview study'. *Disability and Rehabilitation,* 27**,** 1307-1313.

Andrenelli, E., Ippoliti, E., Coccia, M., Millevolte, M., Cicconi, B., Latini, L., Lagalla, G., Provinciali, L., Ceravolo, M. G. & Capecci, M. (2015). 'Features and predictors of activity limitations and participation restriction 2 years after intensive rehabilitation following first-ever stroke'. *European Journal of Physical and Rehabilitation Medicine,* 51**,** 575-85.

Antwi, M. & Kale, M. (2014). *Change Management in Healthcare - Literature Review. The Monieson Centre for Business Research in Healthcare, Queen's University School of Business.* Available: https://smith.queensu.ca/centres/monieson/knowledge_articles/files/Change%20Management%20in%20Healthcare%20-%20Lit%20Review%20-%20AP%20FINAL.pdf [Accessed 01.12.15]

Appleby, J., Galea, A. & Murray, R. (2014). *The NHS productivity challenge- Experience from the Frontline.* [Online], Available: http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/the-nhs-productivity-challenge-kingsfund-may14.pdf [Accessed 20.02.2016].

Appleton, J. V. & Cowley, S. (1997). 'Analysing clinical practice guidelines. A method of documentary analysis.'. *Journal of Advanced Nursing,* 25**,** 1008-1017.

Baker, S. M., Marshak, H. H., Rice, G. T. & Zimmerman, G. J. (2001). 'Patient participation in physical therapy goal setting'. *Physical Therapy,* 81**,** 1118-26.

Balint, E. (1969). 'The possibilities of patient-centered medicine'. *J Royal college of General Practitioners,* 17**,** 269-276.

Bandura, A. (1991). 'Social Cognitive Theory of Self-Regulation'. *Organisational Behaviour and Human Decision Process,* 50**,** 248-287.

Bandura, A. & Locke, E. (2003). 'Negative self-efficacy and goal effects revisited. '. *The Journal of Applied Psychology,* 88 87-99.

Barnard, R. A., Cruice, M. N. & Playford, E. D. (2010). 'Strategies used in the pursuit of achievability during goal setting in rehabilitation'. *Qualitative Health Research,* 20**,** 239-50.

Bastian, H., Glasziou, P. & Chalmers, I. (2010). 'Seventy-Five Trials and Eleven Systematic Reviews a Day: How Will We Ever Keep Up?'. *PLoS Medicine,* 7**,** e1000326.

Baumann, M., Le Bihan, E., Chau, K. & Chau, N. (2014). 'Associations between quality of life and socioeconomic factors, functional impairments and dissatisfaction with received information and home-care services among survivors living at home two years after stroke onset'. *BMC Neurology,* 14**,** 92.

Baxter, S. K. & Brumfitt, S. M. (2008). 'Once a week is not enough: evaluating current measures of teamworking in stroke'. *Journal of Evaluation in Clinical Practice,* 14**,** 241-7.

Bendz, M. (2000). 'Rules of relevance after a stroke'. *Social Science and Medicine,* 51**,** 713.

Bendz, M. (2003). 'The first year of rehabilitation after a stroke – from two perspectives'. *Scandinavian Journal of Caring Sciences,* 17**,** 215-222.

Berkhof, M., van Rijssen, H. J., Schellart, A. J. M., Anema, J. R. & van der Beek, A. J. (2011). 'Effective training strategies for teaching communication skills to physicians: An overview of systematic reviews'. *Patient Education and Counseling,* 84**,** 152-162.

Bero, L. A., Grilli, R., Grimshaw, J. M., Harvey, E., Oxman, A. D. & Thomson, M. A. (1998). 'Closing the gap between research and practice: an overview of systematic reviews of interventions to promote the implementation of research findings'. *British Medical Journal,* 317**,** 465-468.

Bertilsson, A.-S., Ranner, M., von Koch, L., Eriksson, G., Johansson, U., Ytterberg, C., Guidetti, S. & Tham, K. (2014). 'A client-centred ADL intervention: three-month follow-up of a randomized controlled trial'. *Scandinavian Journal of Occupational Therapy,* 21**,** 377-391.

Berwick, D. A. (2013). *A promise to learn – a commitment to act: Improving the Safety of Patients in England.*London: National Advisory Group on the Safety of Patients in England.

Blaikie, N. (2007). *Approaches to social enquiry: Advancing Knowledge.* Cambridge Polity press.

Boonstra, A. M., Wijbrandi, W. & Spikman, J. M. (2005). 'Domiciliary therapy during inpatient rehabilitation treatment for patients with an acquired brain injury: a preliminary study'. *International Journal of Rehabilitation Research,* 28**,** 211.

Booth, A. (2006). '‘‘Brimful of STARLITE’’: toward standards for reporting literature searches'. *Journal of Medical Library Association,* 94**,** 421-430.

Boutin-Lester, P. & Gibson, R. W. (2002). 'Patients’ perceptions of home health occupational therapy'. *Australian Occupational Therapy Journal,* 49**,** 146-154.

Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., Bakken, S., Kaplan, C. P., Squiers, L., Fabrizio, C. & Fernandez, M. (2009). 'How we design feasibility studies'. *American Journal of Preventive Medicine,* 36**,** 452-7.

Bowen, G. A. (2009). 'Document Analysis as a Qualitative Research Method'. *Qualitative Research Journal,* 9**,** 27-40.

Bowling, A. (1997). *Research methods in health: investigating health and health services*. Buckingham: Open University.

Brashler, R. (2006). 'Ethics, family caregivers, and stroke'. *Topics in Stroke Rehabilitation,* 13**,** 11-17.

Brauer, D. J., Schmidt, B. J. & Pearson, V. (2001). 'A Framework for Care During the Stroke Experience'. *Rehabilitation Nursing,* 26**,** 88-93.

Brewer, L., Horgan, F., Hickey, A. & Williams, D. (2013). 'Stroke rehabilitation: recent advances and future therapies'. *Quarterly Journal of Medicine,* 106**,** 11-25.

Broetz, D. & Birbaumer, N. (2013). 'Behavioral physiotherapy in post stroke rehabilitation'. *Neurorehabilitation,* 33**,** 377.

Brown, M., Levack, W., McPherson, K. M., Dean, S. G., Reed, K., Weatherall, M. & Taylor, W. J. (2014). 'Survival, momentum, and things that make me 'me': patients' perceptions of goal setting after stroke'. *Disability and Rehabilitation,* 36**,** 1020-1026.

Burnes, B. (2004). 'Kurt Lewin and the Planned Approach to Change: A Re-appraisal'. *Journal of Management Studies,* 41**,** 977-1002.

Cahill, N. E., Suurdt, J., Ouellette-Kuntz, H. & Heyland, D. K. (2010). 'Understanding adherence to guidelines in the intensive care unit: development of a comprehensive framework'. *Journal of Parenteral and Enteral Nutrition,* 34**,** 616-24.

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L. & Sandercock, P. (2000). 'Framework for design and evaluation of complex interventions to improve health'. *British Medical Journal,* 321 694-6.

Carlsson, G. E., Moller, A. & Blomstrand, C. (2004). 'A qualitative study of the consequences of 'hidden dysfunctions' one year after a mild stroke in persons less than 75 years'. *Disability and Rehabilitation,* 26**,** 1373-80.

Centre for Reviews and Dissemination (CRD) (2009). *Systematic Reviews: CRD's guidance for undertaking reviews in health care.* University of York: CRD.

Chemerinski, E., Robinson, R. G. & Kosier, J. T. (2001). 'Improved Recovery in Activities of Daily Living Associated With Remission of Poststroke Depression'. *Stroke,* 32**,** 113-117.

Chronically Sick and Disabled Persons Act 1970. *C 44.* London: Her Majesty's Stationery Office.

Combs, S. A., Kelly, S. P., Barton, R., Ivaska, M. & Nowak, K. (2010). 'Effects of an intensive, task-specific rehabilitation program for individuals with chronic stroke: A case series'. *Disability and Rehabilitation,* 32**,** 669-678.

Cook, D. J., Mulrow, C. D. & Haynes, R. B. (1997). 'Systematic Reviews: Synthesis of Best Evidence for Clinical Decisions'. *Annals of Internal Medicine,* 126**,** 376-380.

Cooke, A., Smith, D. & Booth, A. (2012). 'Beyond PICO: the SPIDER tool for qualitative evidence synthesis'. *Qualitative Health Research,* 22**,** 1435-43.

Cooper, H., Carlisle, C., Watkins, C. & Gibbs, T. (2001). 'Using Qualitative methods for conducting a systematice review'. *Nurse Researcher,* 8**,** 28-38.

Cott, C. A. (2004). 'Client-centred rehabilitation: client perspectives'. *Disability and Rehabilitation,* 26**,** 1411-1422.

Coulter, A. (2002). 'After Bristol: putting patients at the centre'. *British Medical Journal,* 324**,** 648-651.

Coulter, A., Roberts, S. & Dixon, A. (2013). *Delivering better services for people with long-term conditions-Building the house of care.*London: The King's Fund.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. (2008). Developing and evaluating complex interventions: new guidance Available: www.mrc.ac.uk/complexinterventionsguidance.

Creswell, J. W. (2013). 'Designing a Qualitative Study'. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches.* 3rd ed. London: Sage

Crotty, M. (1998). *The foundations of Social Research – Meaning and perspective in the research process.* London: Sage.

Cumming, T. B., Thrift, A. G., Collier, J. M., Churilov, L., Dewey, H. M., Donnan, G. A. & Bernhardt, J. (2011). 'Very early mobilization after stroke fast-tracks return to walking: further results from the phase II AVERT randomized controlled trial'. *Stroke,* 42**,** 153-8.

Dalley, J. (1999). 'Evaluation of Clinical Practice'. *Physiotherapy,* 85**,** 491-497.

Daniel, K., Wolfe, C. D. A., Busch, M. A. & McKevitt, C. (2009). 'What Are the Social Consequences of Stroke for Working-Aged Adults?: A Systematic Review'. *Stroke,* 40**,** e431-440.

Daniels, R., Winding, K. & Borell, L. (2002). 'Experiences of occupational therapists in stroke rehabilitation: dilemmas of some occupational therapists in inpatient stroke rehabilitation'. *Scandinavian Journal of Occupational Therapy,* 9**,** 167-175.

Darzi, A. (2008). *High Quality Care for All.* London: Department of Health.

Deci, E. L. & Ryan, R. M. (2000). 'The "What" and "Why" of Goal Pursuits: Human Needs and the Self-Determination of Behavior'. *Psychological Inquiry,* 11**,** 227-268.

Demetrios, M., Khan, F., Turner-Stokes, L., Brand, C. & McSweeney, S.(2013) Multidisciplinary rehabilitation following botulinum toxin and other focal intramuscular treatment for post-stroke spasticity *Cochrane Database of Systematic Reviews* Issue 6. Cd009689

Department of Health. (1991). *The Health of The Nation.*London: Her Majesty's Stationery Office.

Department of Health. (2010a). *Equity and Excellence: Liberating the NHS.*London: Her Majesty's Stationery office.

Department of Health. (2010b). *Equity and Excellence: Liberating the NHS.*London: Department of Health.

Department of Health. (2013). *The NHS Constitution.*London: Department of Health.

Department of Health (DoH). (2001). *National Service Framework for Older People.*London: Department of Health.

Department of Health (DoH). (2005). *National Service Framework for Long-term conditions.*London: Department of Health. .

Department of Health (DoH). (2010). *Equity and excellence: Liberating the NHS.*London:

Department of Health (DoH). (2013). *Patients First and Foremost-The Initial Government Response to the Report of The Mid Staffordshire NHS Foundation Trust Public Inquiry.*Norwich: The Stationery Office.

Deutsch, J. E., Maidan, I. & Dickstein, R. (2012). 'Patient-centered integrated motor imagery delivered in the home with telerehabilitation to improve walking after stroke'. *Physical Therapy,* 92**,** 1065.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. & Sutton, A. (2004). *Integrative approaches to qualitative and quantitative evidence.*London: Health Development Agency.

Dixon-Woods, M., Baker, R., Charles, K., Dawson, J., Jerzembek, G., Martin, G., McCarthy, I., McKee, L., Minion, J., Ozieranski, P., Willars, J., Wilkie, P. & West, M. (2013). 'Culture and behaviour in the English National Health Service: overview of lessons from a large multimethod study'. *BMJ Quality and Safety***,** 106-115.

Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Katbamna, S., Olsen, R., Smith, L., Riley, R. & Sutton, A. J. (2006). Conducting a critical interpretative synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology* [Online], 6. Available: http://bmcmedresmethodol.biomedcentral.com/articles/10.1186/1471-2288-6-35.

Dixon, G., Thornton, E. W. & Young, C. A. (2007). 'Perceptions of self-efficacy and rehabilitation among neurologically disabled adults'. *CLINICAL REHABILITATION,* 21**,** 230.

Dohan, D. & Sánchez-Jankowski, M. (1998). 'Using Computers to Analyze Ethnographic Field Data: Theoretical and Practical Considerations'. *Annual Review of Sociology,* 24**,** 477-498.

Ducharme, F. & Trudeau, D. (2002). 'Qualitative evaluation of a stress management intervention for elderly caregivers at home: a constructivist approach'. *Issues in Mental Health Nursing,* 23**,** 691-713.

Duff, J. (2009). 'Team Assessment in Stroke Rehabilitation'. *Topics in Stroke Rehabilitation,* 16**,** 411-419.

Duggan, P. S., Geller, G., Cooper, L. A. & Beach, M. C. (2006). 'The moral nature of patient-centeredness: is it "just the right thing to do"?'. *Patient Education and Counseling,* 62**,** 271-6.

Duncan, P. W., Zorowitz, R., Bates, B., Choi, J. Y., Glasberg, J. J., Graham, G. D., Katz, R. C., Lamberty, K. & Reker, D. (2005). 'Management of Adult Stroke Rehabilitation Care: a clinical practice guideline'. *Stroke,* 36**,** e100-43.

Easton, K. L., McComish, J. F. & Greenberg, R. (2000). 'Avoiding common pitfalls in qualitative data collection and transcription'. *Qualitative Health Research,* 10**,** 703-7.

Elsworth, J. D., Marks, J. A., McGrath, J. R. & Wade, D. T. (1999). 'An audit of goal planning in rehabilitation'. *Topics in Stroke Rehabilitation,* 6**,** 51-61.

Engel, G. (1977). 'The need for a New Medical Model: A challenge for Biomedicine'. *Science,* 196**,** 129-136.

Epstein, R. M. & Street, R. L. (2011). 'The Values and Value of Patient-Centered Care'. *Annals of Family Medicine,* 9**,** 100-103.

Faculty of Public Health. (2012). *Health and Social Care Bill: Risk Assessment Summary.*London: Faculty of Public Health.

Feigin, V. L., Forouzanfar, M. H., Krishnamurthi, R., Mensah, G. A., Connor, M., Bennett, D. A., Moran, A. E., Sacco, R. L., Anderson, L., Truelsen, T., O'Donnell, M., Venketasubramanian, N., Barker-Collo, S., Lawes, C. M. M., Wang, W., Shinohara, Y., Witt, E., Ezzati, M., Naghavi, M., Murray, C., on behalf of the Global Burden of Diseases, Injuries Risk Factors Study & the G. B. D. Stroke Experts Group (2014). 'Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010'. *Lancet,* 383**,** 245-254.

Ferguson, A., Worrall, L. & Sherratt, S. (2009). 'The impact of communication disability on interdisciplinary discussion in rehabilitation case conferences'. *Disability and Rehabilitation,* 31**,** 1795-807.

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.*London: The Stationery Office.

Furlan, A. D., Pennick, V., Bombardier, C. & van Tulder, M. (2009). '2009 updated method guidelines for systematic reviews in the Cochrane Back Review Group'. *Spine,* 34**,** 1929-41.

Gallagher, P. L., Londrigan, M. T. & Levin, R. (2009). 'Partnership for healthy living: an action research project'. *Nurse Researcher,* 16**,** 7-29.

Galvin, J., Randall, M., Hewish, S., Rice, J. & MacKay, M. T. (2010). 'Family-centred outcome measurement following paediatric stroke'. *Australian Occupational Therapy Journal,* 57**,** 152-8.

Gibbon, B. (1999). 'An investigation of interprofessional collaboration in stroke rehabilitation team conferences'. *Journal of Clinical Nursing,* 8**,** 246-252.

Gill, T. M. (1995). 'Quality of life assessment: values and pitfalls'. *Journal of the Royal Society of Medicine,* 88**,** 680-682.

Glass, T. A., Matchar, D. B., Belyea, M. & Feussner, J. R. (1993). 'Impact of social support on outcome in first stroke'. *Stroke,* 24**,** 64-70.

Glazier, S. R., Schuman, J., Keltz, E., Vally, A. & Glazier, R. H. (2004). 'Taking the Next Steps in Goal Ascertainment: A Prospective Study of Patient, Team, and Family Perspectives Using a Comprehensive Standardized Menu in a Geriatric Assessment and Treatment Unit'. *Journal of the American Geriatrics Society,* 52**,** 284-289.

Grant, A. (2005). 'The use of qualitative research methodologies within musculoskeletal physiotherapy practice'. *Manual Therapy,* 10**,** 1-3.

Grbich, C. (1999). *Qualitative research in health: an introduction.* London: Sage.

Green, J. & Thorogood, N. (2009). *Qualitative methods for health research* 2nd ed. Thousand Oaks, CA: Sage.

Green, L. A. & Seifert, C. M. (2005). 'Translation of Research Into Practice: Why We Can't "Just Do It"'. *Journal of American Board of Family Practice,* 18**,** 541-5.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P. & Kyriakidou, O. (2004). 'Diffusion of innovations in service organizations: systematic review and recommendations'. *Milbank Quarterly,* 82**,** 581-629.

Grol, R. P. T. M., Bosch, M. C., Hulscher, M. E. J. L., Eccles, M. P. & Wensing, M. (2007). 'Planning and Studying Improvement in Patient Care: The Use of Theoretical Perspectives'. *The Milbank quarterly,* 85**,** 93-138.

Guidetti, S. & Tham, K. (2002). 'Therapeutic strategies used by occupational therapists in self-care training: a qualitative study'. *Occupational Therapy International,* 9**,** 257-276.

Gunnel, E. C., Anders, M. & Christian, B. (2009). 'Managing an everyday life of uncertainty – A qualitative study of coping in persons with mild stroke'. *Disability and Rehabilitation,* 31**,** 773–782.

Gustafsson, L., Fleming, J., Cornwell, P., Worrall, L. & Brauer, S. (2014). 'STRENGTH and the Health Care Team: Changing Interprofessional and Client-Centered Practices'. *Topics in Stroke Rehabilitation,* 21**,** 413-420.

Gustafsson, L. & McLaughlin, K. (2009). 'An exploration of clients' goals during inpatient and outpatient stroke rehabilitation'. *International Journal of Therapy and Rehabilitation,* 16**,** 324-330.

Gzil, F., Lefeve, C., Cammelli, M., Pachoud, B., Ravaud, J. F. & Leplege, A. (2007). 'Why is rehabilitation not yet fully person-centred and should it be more person-centred?'. *Disability and Rehabilitation,* 29**,** 1616-24.

Hackett, M. L., Duncan, J. R., Anderson, C. S., Broad, J. B. & Bonita, R. (2000). 'Health-Related Quality of Life Among Long-Term Survivors of Stroke: Results From the Auckland Stroke Study, 1991–1992'. *Stroke,* 31**,** 440-447.

Hackett, M. L., Yapa, C., Parag, V. & Anderson, C. S. (2005). 'Frequency of depression after stroke: a systematic review of observational studies'. *Stroke,* 36**,** 1330-40.

Hafsteinsdóttir, T. B. & Grypdonck, M. (1997). 'Being a stroke patient: a review of the literature'. *Journal of Advanced Nursing,* 26**,** 580-588.

Hale, L. A. & Piggot, J. (2005). 'Exploring the content of physiotherapeutic home-based stroke rehabilitation in New Zealand'. *Archives of Physical Medicine and Rehabilitation,* 86**,** 1933-1940.

Haley, W. E., Roth, D. L., Kissela, B., Perkins, M. & Howard, G. (2011). 'Quality of life after stroke: a prospective longitudinal study'. *Quality of Life Research,* 20**,** 799-806.

Hammersley, M. (2009). 'Why Critical Realism Fails to Justify Critical Social Research'. *Methodological Innovations Online,* 4**,** 1-11.

Harden, A., Brunton, G., Fletcher, A., Oakley, A., Burchett, H. & Backhans, M. (2006). *Young people, pregnancy and social exclusion: A systematic synthesis of research evidence to identify effective, appropriate and promising approaches for prevention and support.*London: Eppi-Centre, S. S. R. U., Institute of Education & University of London.

Hare, R., Rogers, H., Lester, H., McManus, R. J. & Mant, J. (2006). 'What do stroke patients and their carers want from community services ?'. *Family Practice,* 23**,** 131-136.

Health and Care Professions Council (HCPC). (2012). *Standards of Proficiency: Physiotherapists.*London: HCPC.

Health and Social Care Act 2012. *C7.* The Stationery office.

Henshaw, E., Polatajko, H., McEwen, S., Ryan, J. D. & Baum, C. M. (2011). 'Cognitive approach to improving participation after stroke: two case studies'. *American Journal of Occupational Therapy,* 65**,** 55-63.

Hersh, D., Sherratt, S., Howe, T., Worrall, L., Davidson, B. & Ferguson, A. (2012a). 'An analysis of the "goal" in aphasia rehabilitation'. *Aphasiology,* 26**,** 971-984.

Hersh, D., Worrall, L., Howe, T., Sherratt, S. & Davidson, B. (2012b). 'SMARTER goal setting in aphasia rehabilitation'. *Aphasiology,* 26**,** 220-233.

Higgins, J. P. T. & Green, S., (eds) (updated March 2011). *Cochrane Handbook for Systematic Reviews of Interventions* Available: www.cochrane-handbook.org

Holliday, R. C., Antoun, M. & Playford, E. D. (2005). 'A Survey of Goal-Setting Methods Used in Rehabilitation'. *Neurorehabilitation and Neural Repair,* 19**,** 227-231.

Holliday, R. C., Ballinger, C. & Playford, E. D. (2007). 'Goal setting in neurological rehabilitation: patients' perspectives'. *Disability and Rehabilitation,* 29**,** 389-394.

Holliday, R. C., Cano, S., Freeman, J. A. & Playford, E. D. (2007). 'Should patients participate in clinical decision making? An optimised balance block design controlled study of goal setting in a rehabilitation unit'. *Journal of Neurology, Neurosurgery, and Psychiatry,* 78**,** 576-580.

Howard, D. & Davis, P. (2002). 'The use of qualitative research methodology in orthopaedics – tell it as it is'. *Journal of Orthopaedic Nursing,* 6**,** 135-139.

Huby, G., Stewart, J., Tierney, A. & Rogers, W. (2004). 'Planning older people's discharge from acute hospital care: linking risk management and patient participation in decision-making'. *Health, Risk & Society,* 6**,** 115-132.

Human Rights Act 1998. *C 42.* London: Her Majesty's Stationery Office.

Institute of Medicine (IOM) & Committee on the Quality of Health Care in America. (2001). *Crossing the quality chasm: A new health system for the 21st century.*Washington: Institute of Medicine.

Intercollegiate Stroke Working Party. (2012). *National clinical guidelines for stroke (4th ed).*London: Royal College of Physicians.

Intercollegiate Stroke Working Party (ISWP). (2011). *National Sentinel Stroke Clinical Audit 2010 -Round 7.*London: Royal College of Physicians.

International Alliance of Patients' Organisations & (IAPO). (2007). *What is Patient-Centred Healthcare? A review of definitions and principles.*London: IAPO.

John, W. S. & Johnson, P. (2000). 'The Pros and Cons of Data Analysis Software for Qualitative Research'. *Journal of Nursing Scholarship,* 32**,** 393-397.

Johnston, M., Morrison, V., Macwalter, R. & Partridge, C. (1999). 'Perceived control, coping and recovery from disability following stroke'. *Psychology and Health,* 14**,** 181-192.

Jones, F., Mandy, A. & Partridge, C. (2000). 'Who's in control after a stroke? Do we disempower our patients?'. *Physiotherapy Research International,* 5**,** 249-253.

Jones, F., Mandy, A. & Partridge, C. (2008). 'Reasons for recovery after stroke: A perspective based on personal experience'. *Disability and Rehabilitation,* 30 507 – 516.

Jönsson, A.-C., Lindgren, I., Hallström, B., Norrving, B. & Lindgren, A. (2005). 'Determinants of Quality of Life in Stroke Survivors and Their Informal Caregivers'. *Stroke,* 36**,** 803-808.

Jüni, P., Witschi, A., Bloch, R. & Egger, M. (1999). 'THe hazards of scoring the quality of clinical trials for meta-analysis'. *Journal of American Medical Association,* 282**,** 1054-1060.

Kamioka, Y., Yoshino, T., Sugaya, K., Asito, H., Ohashi, Y. & Iijima, S. (2009). 'Goal-setting method and goal attainment measures in physical therapy for stroke patients: A systematic review'. *Journal of Physical Therapy Science,* 21**,** 399.

Kawulich, B. B. (2005). Participant Observation as a Data Collection Method. *Forum Qualitative Sozialforschung* [Online], 6. Available: http://nbn-resolving.de/urn:nbn:de:0114-fqs0502430. [Accessed 31.05.2012].

Kennedy, I. (2001). *Bristol Royal Infirmary Inquiry. Learning from Bristol:the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995.*London: The Stationery Office.

Keogh, B. (2013). *Review into the quality of care and treatment provided by 14 hospital trusts in England: overview report.*London: The Stationery Office.

Khan, K. S., Kunz, R., Kleijnen, J. & Antes, G. (2003). 'Five steps to conducting a systematic review'. *Journal of the Royal Society of Medicine,* 96**,** 118-121.

Kidd, P. S. & Parshall, M. B. (2000). 'Getting the Focus and the Group: Enhancing Analytical Rigor in Focus Group Research'. *Qualitative Health Research,* 10**,** 293-308.

King, I. M. (1997). 'King's Theory of Goal Attainment in Practice'. *Nursing Science Quarterly,* 10**,** 180-185.

Kitzinger, J. (1995). 'Qualitative research. Introducing focus groups'. *British Medical Journal,* 311**,** 299-302.

Kochevar, L. K. & Yano, E. M. (2006). 'Understanding health care organization needs and context. Beyond performance gaps'. *Journal General Internal Medicine,* 21 Suppl 2**,** S25-9.

Kolakowski, L. (2004). 'An Overall View of Positivism'. in: Hammersley, M. (ed.) *Social Research Philosophy, Politics and Practice.* London: Sage.1-8.

Krefting, L. (1991). 'Rigor in Qualitative Research: The Assessment of Trustworthiness'. *The American journal of occupational therapy,* 45**,** 214-222.

Krishnamurthi, R. V., Feigin, V. L., Forouzanfar, M. H., Mensah, G. A., Connor, M., Bennett, D. A., Moran, A. E., Sacco, R. L., Anderson, L. M., Truelsen, T., O'Donnell, M., Venketasubramanian, N., Barker-Collo, S., Lawes, C. M. M., Wang, W., Shinohara, Y., Witt, E., Ezzati, M., Naghavi, M. & Murray, C. (2013). 'Global and regional burden of first-ever ischaemic and haemorrhagic stroke during 1990–2010: findings from the Global Burden of Disease Study 2010'. *The Lancet Global Health,* 1**,** e259-e281.

Kus, S., Muller, M., Strobl, R. & Grill, E. (2011). 'Patient goals in post-acute geriatric rehabilitation--goal attainment is an indicator for improved functioning'. *Journal of Rehabilitation Medicine,* 43**,** 156-61.

Laine, C. & Davidoff, F. (1996). 'Patient-centered medicine: a professional evolution. '. *Journal of American Medical Association,* 275**,** 152-156.

Langhorne, P. & Pollock, A. (2002). 'What are the components of effective stroke unit care?'. *Age Ageing,* 31**,** 365-71.

Laver, K., Lannin, N. A., Bragge, P., Hunter, P., Holland, A. E., Tavender, E., O'Connor, D., Khan, F., Teasell, R. & Gruen, R. (2014). 'Organising health care services for people with an acquired brain injury: an overview of systematic reviews and randomised controlled trials'. *BMC Health Services Research,* 14**,** 397.

Laver, K. M., Halbert, J., Stewart, M. M. & Crotty, M. (2010). 'Patient Readiness and Ability to Set Recovery Goals During the First 6 Months After Stroke'. *Journal of Allied Health,* 39**,** e149-54.

Lawler, J., Dowswell, G., Hearn, J., Forster, A. & Young, J. (1999). 'Recovering from stroke: a qualitative investigation of the role of goal setting in late stroke recovery'. *Journal of Advanced Nursing,* 30**,** 401.

Lawrence, E. S., Coshall, C., Dundas, R., Stewart, J., Rudd, A. G., Howard, R. & Wolfe, C. D. (2001). 'Estimates of the prevalence of acute stroke impairments and disability in a multiethnic population'. *Stroke,* 32**,** 1279-84.

Lawrence, M. & Kinn, S. (2012). 'Defining and measuring patient-centred care: an example from a mixed-methods systematic review of the stroke literature'. *Health Expectations,* 15**,** 295-326.

Laws, D. & Amato, S. (2010). 'Incorporating bedside reporting into change-of-shift report'. *Rehabilitation Nursing,* 35**,** 70.

Leach, E., Cornwell, P., Fleming, J. & Haines, T. (2010). 'Patient centered goal-setting in a subacute rehabilitation setting'. *Disability & Rehabilitation,* 32**,** 159-172.

Lee, S., Shafe, A. C. & Cowie, M. R. (2011). 'UK stroke incidence, mortality and cardiovascular risk management 1999-2008: time-trend analysis from the General Practice Research Database'. *British Medical Journal Open,* 1**,** e000269.

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B. & Ville, I. (2007). 'Person-centredness: Conceptual and historical perspectives'. *Disability and Rehabilitation,* 29**,** 1555 – 1565.

Levack, W. M., Dean, S. G., Siegert, R. J. & McPherson, K. M. (2011). 'Navigating patient-centered goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities'. *Patient Education and Counseling,* 85**,** 206-13.

Levack, W. M., Siegert, R. J., Dean, S. G. & McPherson, K. M. (2009). 'Goal planning for adults with acquired brain injury: how clinicians talk about involving family'. *Brain Injury,* 23**,** 192-202.

Levack, W. M. M., Dean, S. G., Siegert, R. J. & McPherson, K. M. (2006a). 'Purposes and mechanisms of goal planning in rehabilitation: the need for a critical distinction'. *Disability and Rehabilitation,* 28**,** 741-9.

Levack, W. M. M., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M. & Weatherall, M. (2006b). 'Is goal planning in rehabilitation effective? A systematic review'. *Clinical Rehabilitation,* 20**,** 739-755.

Lindsay, M. P., Gubitz, G., Bayley, M., Hill, M. D., Davies-Schinkel, C., Singh, S. & Phillips, S. (2010). Canadian Best Practice Recommendations for Stroke Care. Ontario: Canadian Stroke Network.

Lingard, L., Albert, M. & Levinson, W. (2008). 'Grounded theory, mixed methods, and action research'. *British Medical Journal,* 337**,** a567.

Lloyd, A., Roberts, A. R. & Freeman, J. A. (2014). "Finding a Balance' in Involving Patients in Goal Setting Early After Stroke: A Physiotherapy Perspective'. *Physiotherapy Research International,* 19**,** 147-157.

Locke, E. A. (1996). 'Motivation through conscious goal setting'. *Applied and Preventive Psychology,* 5**,** 117-124.

Locke, E. A. & Latham, G. P. (2006). 'New Directions in Goal-Setting Theory'. *Current Directions in Psychological Science,* 15**,** 265-268.

Lozano, R., Naghavi, M., Foreman, K., Lim, S., Shibuya, K., Aboyans, V., Abraham, J., Adair, T., Aggarwal, R., Ahn, S. Y., AlMazroa, M. A., Alvarado, M., Anderson, H. R., Anderson, L. M., Andrews, K. G., Atkinson, C., Baddour, L. M., Barker-Collo, S., Bartels, D. H., Bell, M. L., Benjamin, E. J., Bennett, D., Bhalla, K., Bikbov, B., Abdulhak, A. B., Birbeck, G., Blyth, F., Bolliger, I., Boufous, S., Bucello, C., Burch, M., Burney, P., Carapetis, J., Chen, H., Chou, D., Chugh, S. S., Coffeng, L. E., Colan, S. D., Colquhoun, S., Colson, K. E., Condon, J., Connor, M. D., Cooper, L. T., Corriere, M., Cortinovis, M., de Vaccaro, K. C., Couser, W., Cowie, B. C., Criqui, M. H., Cross, M., Dabhadkar, K. C., Dahodwala, N., De Leo, D., Degenhardt, L., Delossantos, A., Denenberg, J., Des Jarlais, D. C., Dharmaratne, S. D., Dorsey, E. R., Driscoll, T., Duber, H., Ebel, B., Erwin, P. J., Espindola, P., Ezzati, M., Feigin, V., Flaxman, A. D., Forouzanfar, M. H., Fowkes, F. G. R., Franklin, R., Fransen, M., Freeman, M. K., Gabriel, S. E., Gakidou, E., Gaspari, F., Gillum, R. F., Gonzalez-Medina, D., Halasa, Y. A., Haring, D., Harrison, J. E., Havmoeller, R., Hay, R. J., Hoen, B., Hotez, P. J., Hoy, D., Jacobsen, K. H., James, S. L., Jasrasaria, R., Jayaraman, S., Johns, N., Karthikeyan, G., Kassebaum, N., Keren, A., Khoo, J.-P., Knowlton, L. M., Kobusingye, O., Koranteng, A., Krishnamurthi, R., Lipnick, M., Lipshultz, S. E*., et al.* (2012). 'Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: a systematic analysis for the Global Burden of Disease Study 2010'. *The Lancet,* 380**,** 2095-2128.

Luxford, K., Safran, D. G. & Delbanco, T. (2011). 'Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation

for improving the patient experience'. *International Journal for Quality in Health Care,* 23**,** 510-515.

Maclean, N., Pound, P., Wolfe, C. & Rudd, A. (2000). 'Qualitative analysis of stroke patients' motivation for rehabilitation'. *British Medical Journal,* 321**,** 1051-1054.

Maclean, N., Pound, P., Wolfe, C. & Rudd, A. (2002). 'The Concept of Patient Motivation: A Qualitative Analysis of Stroke Professionals' Attitudes'. *Stroke,* 33**,** 444-448.

Maitra, K. K. & Erway, F. (2006). 'Perception of client-centered practice in occupational therapists and their clients'. *American Journal of Occupational Therapy,* 60**,** 298.

Management of Stroke Rehabilitation Working Group (2010). The Management of Stroke Rehabilitation. . Washington: Department of Veterans Affairs, Department of Defense.

Maslow, A. H. (1943). 'A Theory of Human Motivation'. *Psychological Review,* 50**,** 370-396.

Mason, M. (2010). Sample Size and Saturation in PhD studies using Qualitative Interviews. *Forum: Qualitative Social Research* [Online], [S.l.], v. 11. Available: http://www.qualitative-research.net/index.php/fqs/article/view/1428/3028.

Mathison, S. (1988). 'Why Triangulate?'. *Educational Researcher,* 17**,** 13-17.

Maxwell, J. A. (2005). *Qualitative Research Design. An Interactive approach.* 2nd ed. London: Sage.

Mays, N. & Pope, C. (1995). 'Qualitative research: Observational methods in health care settings'. *BMJ : British Medical Journal,* 311**,** 182-184.

McCormack, B. (2003). 'A conceptual framework for person-centred practice with older people'. *International Journal of Nursing Practice,* 9**,** 202-209.

McEwen, S. E., Polatajko, H. J., Huijbregts, M. P. & Ryan, J. D. (2009). 'Exploring a cognitive-based treatment approach to improve motor-based skill performance in chronic stroke: Results of three single case experiments'. *Brain Injury,* 23**,** 1041-1053.

McEwen, S. E., Polatajko, H. J., Huijbregts, M. P. J. & Ryan, J. D. (2010). 'Inter-task transfer of meaningful, functional skills following a cognitive-based treatment: Results of three multiple baseline design experiments in adults with chronic stroke'. *Neuropsychological Rehabilitation,* 20**,** 541-561.

McGrath, J. R. & Adams, L. (1999). 'Patient-centered goal planning: a systemic psychological therapy?'. *Topics in Stroke Rehabilitation,* 6**,** 43-50.

McKellar, J. M., Cheung, D., Lowe, M., Willems, J., Heus, L. & Parsons, J. (2011). 'Healthcare providers' perspectives on an interprofessional education intervention for

promoting community re-engagement post stroke'. *Journal of Interprofessional Care,* 25**,** 380-382.

McLaren, N. (1998). 'A critical review of the biopsychosocial model'. *Australian and NewZealand Journal of Psychiatry,* 32**,** 86-92.

Mead, M. & Bower, P. (2000). 'Patient-centredness: a conceptual framework and review of the empirical literature'. *Social Sciences and Medicine,* 51**,** pp.1087-1110.

Medical Research Council (MRC) (2000). *A framework for the development and evaluation of RCTs for complex interventions to improve health.* London: Medical Research Council.

Mehay, R., Beaumont, R., Draper, J., Lamb, I., Moulton, L. & Kenny, D. (2012). 'Revisiting Models of Consultation'. in: Mehay, R. (ed.) *The Essential Handbook for GP Training and Education.* London: Radcliffe Publishing

Michie, S., Miles, J. & Weinman, J. (2003). 'Patient-centredness in chronic illness: what is it and does it matter?'. *Patient Education and Counseling,* 51**,** 197-206.

Miles, M. B. & Huberman, A. M. (1994). *An expanded source book: Qualitative data analysis* 2nd ed. CA: Sage.

Miles, M. B., Huberman, A. M. & Saldana, J. (2014). 'Drawing and Verifying Conclusions'. *Qualitative Data Analysis-A Methods Sourcebook.* 3rd ed. London: Sage

Mills, J., Bonner, A. & Francis, K. (2006). 'Adopting a constructivist approach to grounded theory: implications for research design'. *International Journal of Nursing Practice,* 12**,** 8-13.

Mingers, J. (2006). *Philosophical Foundations: Critical Realism*. *Realising Systems Thinking: Knowledge and Action in Management Science* [Online]. Available: http://www.springer.com/978-0-387-28188-9 [Accessed 2.4.15]

Moher, D., Hopewell, S., Schulz, K. F., Montori, V., Gøtzsche, P. C., Devereaux, P. J., Elbourne, D., Egger, M. & Altman, D. G. (2010). 'CONSORT 2010 Explanation and Elaboration: updated guidelines for reporting parallel group randomised trials'. *Journal of Clinical Epidemiology,* 63**,** e1-37.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G. & The PRISMA Group (2009). 'Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement'. *PLoS Medicine,* 6**,** 1-6. e1000097. doi:10.1371/journal.pmed1000097

Moher, D. & Tsertsvadze, A. (2006). 'Systematic reviews: when is an update an update?'. *The Lancet,* 367**,** 881-883.

Monaghan, J., Channell, K., McDowell, D. & Sharma, A. K. (2005). 'Improving patient and carer communication, multidisciplinary team working and goal-setting in stroke rehabilitation'. *Clinical Rehabilitation,* 19**,** 194-199.

Morgan, S. & Yoder, L. H. (2012). 'A Concept Analysis of Person-Centered Care'. *Journal of Holistic Nursing,* 30**,** 6-15.

Mulhall, A. (2003). 'In the field: notes on observation in qualitative research'. *Journal of Advanced Nursing,* 41**,** 306-313.

Murray, C. J. L., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., Ezzati, M., Shibuya, K., Salomon, J. A., Abdalla, S., Aboyans, V., Abraham, J., Ackerman, I., Aggarwal, R., Ahn, S. Y., Ali, M. K., AlMazroa, M. A., Alvarado, M., Anderson, H. R., Anderson, L. M., Andrews, K. G., Atkinson, C., Baddour, L. M., Bahalim, A. N., Barker-Collo, S., Barrero, L. H., Bartels, D. H., Basáñez, M.-G., Baxter, A., Bell, M. L., Benjamin, E. J., Bennett, D., Bernabé, E., Bhalla, K., Bhandari, B., Bikbov, B., Abdulhak, A. B., Birbeck, G., Black, J. A., Blencowe, H., Blore, J. D., Blyth, F., Bolliger, I., Bonaventure, A., Boufous, S., Bourne, R., Boussinesq, M., Braithwaite, T., Brayne, C., Bridgett, L., Brooker, S., Brooks, P., Brugha, T. S., Bryan-Hancock, C., Bucello, C., Buchbinder, R., Buckle, G., Budke, C. M., Burch, M., Burney, P., Burstein, R., Calabria, B., Campbell, B., Canter, C. E., Carabin, H., Carapetis, J., Carmona, L., Cella, C., Charlson, F., Chen, H., Cheng, A. T.-A., Chou, D., Chugh, S. S., Coffeng, L. E., Colan, S. D., Colquhoun, S., Colson, K. E., Condon, J., Connor, M. D., Cooper, L. T., Corriere, M., Cortinovis, M., de Vaccaro, K. C., Couser, W., Cowie, B. C., Criqui, M. H., Cross, M., Dabhadkar, K. C., Dahiya, M., Dahodwala, N., Damsere-Derry, J., Danaei, G., Davis, A., Leo, D. D., Degenhardt, L., Dellavalle, R., Delossantos, A., Denenberg, J., Derrett, S., Des Jarlais, D. C*., et al.* (2012). 'Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010'. *The Lancet,* 380**,** 2197-2223.

Murray, J., Young, J., Forester, A. & Ashworth, R. (2003). 'Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers'. *British Journal of General Practice,* 53**,** 803-807.

National Audit Office (NAO). (2010). *Progress in improving stroke care* London: : The Stationary Office.

National Collaborating Centre for Methods and Tools (NCCMT). (2013). *Defining your question for finding qualitative research: SPIDER tool*. Available: http://www.nccmt.ca/resources/search/191

National Institute for Health and Care Excellence (NICE). (2013). *Stroke Rehabilitation, Long term rehabilitation after stroke.*Clinical guideline 162, Manchester: National Clinical Guideline Centre.

National Quality Board. (2013). *Quality in the new health system - Maintaining and improving quality from April 2013.*London: Nqb.

NHS Institute for Innovation and Improvement. (2006-2013). *Quality and Service Improvement tools* [Online]. NHS Institute for Innovation and Improvement Available: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/quality_and_service_improvement_tools_for_the_nhs.html [Accessed 05.01.15 2015].

Nichols-Larsen, D. S., Clark, P. C., Zeringue, A., Greenspan, A. & Blanton, S. (2005). 'Factors influencing stroke survivors' quality of life during subacute recovery'. *Stroke,* 36**,** 1480-4.

Nordehn, G., Meredith, A. & Bye, L. (2006). 'A Preliminary Investigation of Barriers to Achieving Patient-Centered Communication with Patients Who Have Stroke-Related Communication Disorders'. *Topics in Stroke Rehabilitation,* 13**,** 68-77.

Northen, J. G., Rust, D. M., Nelson, C. E. & Watts, J. H. (1995). 'Involvement of Adult Rehabilitation Patients in Setting Occupational Therapy Goals'. *American Journal of Occupational Therapy,* 49**,** 214-220.

Nott, M. T., Barden, H. L. & Baguley, I. J. (2014). 'Goal attainment following upper-limb botulinum toxin-A injections: are we facilitating achievement of client-centred goals?'. *Journal of Rehabilitation Medicine,* 46**,** 864-8.

Ogilvie, D., Hamilton, V., Egan, M. & Petticrew, M. (2005). 'Systematic reviews of health effects of social interventions: 1. Finding the evidence: how far should you go?'. *Journal of Epidemiology and Community Health,* 59**,** 804-8.

Ozer, M. N. & Kroll, T. (2002). 'Patient-Centered Rehabilitation: Problems and Opportunities'. *Critical Reviews in Physical Rehabilitation Medicine,* 14**,** 273-89.

Parry, R. H. (2004). 'Communication during goal-setting in physiotherapy treatment sessions'. *Clinical Rehabilitation,* 18**,** 668-682.

Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods.* 3rd ed. London: Sage.

Patton, M. Q. (2015). *Qualitative Research and Evaluation Methods.* 4th. Thousand Oaks, California: Sage.

Pawson, R., Boaz, A., Grayson, L., Long, A. & Barnes, C. (2003). *Types and quality of social care knowledge Stage two: towards the quality assessment of social care knowledge.*London: Social Care Institute for Excellence.

Pawson, R. & Tilley, N. (1997). *Realistic Evaluation.* London: Sage.

Phipps, S. & Richardson, P. (2007). 'Occupational therapy outcomes for clients with traumatic brain injury and stroke using the Canadian Occupational Performance Measure'. *American Journal of Occupational Therapy,* 61**,** 328-34.

Picker Institute. (1987). *Clarification of the history of the Picker Institute's eight principles of patient-centred care*. Available: http://www.strategicprojectseoe.co.uk/uploads/files/Picker%20Institute%20Principles%20of%20Patient%20Centre%20Care%20history.pdf

Playford, E. D., Dawson, L., Limbert, V., Smith, M., Ward, C. D. & Wells, R. (2000). 'Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting'. *Clinical Rehabilitation,* 14**,** 491-496.

Playford, E. D., Siegert, R., Levack, W. M. & Freeman, J. (2009). 'Areas of consensus and controversy about goal setting in rehabilitation: a conference report'. *Clinical Rehabilitation,* 23**,** 334-344.

Ponterotto, J. G. (2005). 'Qualitative Research in Counseling Psychology: A Primer on Research Paradigms and Philosophy of Science'. *Journal of Counseling Psychology,* 52**,** 126-136.

Pope, C., Ziebland, S. & Mays, N. (2000). 'Qualitative research in health care Analysing qualitative data'. *British Medical Journal,* 320**,** 114-116.

Porter, S. (2007). 'Validity, trustworthiness and rigour: reasserting realism in qualitative research'. *Journal of Advanced Nursing,* 60**,** 79-86.

Pound, P., Sabin, C. & Ebrahim, S. (1999). 'Observing the process of care: a stroke unit, elderly care unit and general medical ward compared'. *Age Ageing,* 28**,** 433-40.

Powell, R. (2014). 'Surveys'. in: Walker, D.-M. (ed.) *An Introduction to Health Services Research.* London Sage

Proot, I. M., Crebolder, H. F. J. M., Abu-Saad, H. H., Macor, T. H. G. M. & Ter Meulen, R. H. J. (2000). 'Stroke patients' needs and experiences regarding autonomy at discharge from nursing home'. *Patient Education and Counseling,* 41**,** 275-283.

Putman, K., de Wit, L., Schupp, W., Ilse, B., Berman, P., Connell, L., Dejaeger, E., de Meyer, A. M., de Weerdt, W., Feys, H., Walter, J., Lincoln, N., Louckx, F., Anneleen, M., Birgit, S., Smith, B. & Leys, M. (2006). 'Use of time by physiotherapists and occupational therapists in a stroke rehabilitation unit: a comparison between four European rehabilitation centres'. *Disability and Rehabilitation,* 28**,** 1417-24.

Raju, R. S., Sarma, P. S. & Pandian, J. D. (2010). 'Psychosocial problems, quality of life, and functional independence among Indian stroke survivors'. *Stroke,* 41**,** 2932-7.

Randall, K. E. & McEwen, I. R. (2000). 'Writing Patient-Centered Functional Goals'. *PHYS THER.,* 2000**,** 1197-1203.

Reed, M., Harrington, R., Duggan, A. & Wood, V. A. (2010). 'Meeting stroke survivors' perceived needs: a qualitative study of a community-based exercise and education scheme'. *Clinical Rehabilitation,* 24**,** 16.

Rees, J., Wilcox, J. R. & Cuddihy, R. A. (2002). 'Psychology in rehabilitation of older adults'. *Reviews in Clinical Gerontology,* 12**,** 343-356.

Rehabilitation act of 1973. *Section 504.* Washington: U S Department of Labour.

Rigby, H., Gubitz, G. & Phillips, S. (2009). 'A systematic review of caregiver burden following stroke'. *International Journal of Stroke,* 4**,** 285-292.

Ritchie, J. & Spencer, L. (1994). 'Qualitative data analysis for applied policy research. '. in: Bryman, A. & Burgess, R. (eds.) *Analysing qualitative data.* London: Routledge.173-94

Roberts, K. (2002). 'Exploring participation: older people on discharge from hospital. '. *Journal of Advanced Nursing,* 40**,** 413-420.

Robinson, N. (1999). 'The use of focus group methodology--with selected examples from sexual health research'. *Journal of Advanced Nursing,* 29**,** 905-13.

Robinson, R. G. (1997). 'Neuropsychiatric consequences of stroke'. *Annual Review of Medicine,* 48**,** 217-29.

Robson, C. (2002). *Real World Research: A Resource for Social Scientists and Practitioner-Researchers.* 2nd ed. Oxford: John Wiley.

Rochette, A. & Desrosiers, J. (2002). 'Coping with the consequences of a stroke'. *International Journal of Rehabilitation Research,* 25**,** 17-24.

Rogers, C. R. (1946). 'Significant aspects of client-centered therapy'. *American Psychologist,* 1**,** 415-422.

Rohde, A., Townley-O'Neill, K., Trendall, K., Worrall, L. & Cornwell, P. (2012). 'A comparison of client and therapist goals for people with aphasia: A qualitative exploratory study'. *Aphasiology,* 26**,** 1298-1315.

Rosewilliam, S., Pandyan, A. D. & Roskell, C. A. (2014). 'Goal Setting in Stroke Rehabilitation: Theory, Practice and Future Directions'. *Rehabilitation Goal Setting.* CRC Press.345-370.

Rosewilliam, S., Roskell, C. A. & Pandyan, A. D. (2011). 'A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation'. *Clinical Rehabilitation,* 25**,** 501-514.

Rosewilliam, S., Roskell, C. A., Pandyan, A. D. & Sintler, C. Do the goals of patients with stroke and the multidisciplinary professional match? An exploratory study investigating patient-centredness in goal-setting. Presented at WCPT congress., 2011 Amsterdam. Physiotherapy, .

Rosewilliam, S., Sintler, C., Pandyan, A. D., Skelton, J. & Roskell, C. A. (2015). 'Is the practice of goal-setting for patients in acute stroke care patient-centred and what factors influence this? A qualitative study'. *Clinical Rehabilitation***,** 0269215515584167.

Rotenberg-Shpigelman, S., Erez, A. B., Nahaloni, I. & Maeir, A. (2012). 'Neurofunctional treatment targeting participation among chronic stroke survivors: a pilot randomised controlled study'. *Neuropsychological Rehabilitation,* 22**,** 532-49.

Royal College of Nursing (RCN). (2010). *Principles of Nursing Practice: principles and measures consultation.*London: Royal College of Nursing.

Royal College of Physicians (RCP). (2015). *Sentinel Stroke National Audit Programme (SSNAP)* [Online]. Available: https://www.rcplondon.ac.uk/projects/outputs/sentinel-stroke-national-audit-programme-ssnap [Accessed 16.03.15 2015].

Ruff, C. C., Alexander, I. M. & McKie, C. (2005). 'The use of focus group methodology in health disparities research'. *Nursing Outlook,* 53**,** 134-40.

Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B. & Richardson, W. S. (1996). 'Evidence based medicine: what it is and what it isn't'. *British Medical Journal,* 312**,** 71-72.

Saha, S., Beach, M. C. & Cooper, L. A. (2008). 'Patient Centeredness, Cultural Competence and Healthcare Quality'. *Journal of the National Medical Association,* 100**,** 1275-1285.

Saka, O., McGuire, A. & Wolfe, C. (2009). 'Cost of stroke in the United Kingdom'. *Age Ageing,* 38**,** 27-32.

Sales, A., Smith, J., Curran, G. & Kochevar, L. (2006). 'Models, Strategies, and Tools Theory in Implementing Evidence-Based Findings into Health Care Practice'. *Journal of General Internal Medicine,* 21**,** S43-S49.

Samsa, G. P. & Matchar, D. B. (2004). 'How strong is the relationship between functional status and quality of life among persons with stroke?'. *Journal of Rehabilitation Research and Development,* 41**,** 279-82.

Sandelowski, M. (1995). 'On the Aesthetics of Qualitative Research'. *Image: the Journal of Nursing Scholarship,* 27**,** 205-209.

Sayer, A. (1997). 'Critical Realism and the Limits to Critical Social Science'. *Journal for the Theory of Social Behaviour,* 27**,** 473-488.

Schein, E. H. (1996). 'Kurt Lewin's Change Theory in the Field and in the Classroom: Notes Toward a Model of Managed Learning'. *Systems Practice,* 9**,** 27-47.

Schein, E. H. (2002). 'Models and Tools for Stability and Change in Human Systems'. *Reflections,* 4**,** 34-46.

Schwamm, L. H., Pancioli, A., Acker, J. E., 3rd, Goldstein, L. B., Zorowitz, R. D., Shephard, T. J., Moyer, P., Gorman, M., Johnston, S. C., Duncan, P. W., Gorelick, P., Frank, J., Stranne, S. K., Smith, R., Federspiel, W., Horton, K. B., Magnis, E., Adams, R. J. & American Stroke Association's Task Force on the Development of Stroke, S. (2005). 'Recommendations for the establishment of stroke systems of care: recommendations from the American Stroke Association's Task Force on the Development of Stroke Systems'. *Circulation,* 111**,** 1078-91.

Schwarzer, R. (1992). 'Self-efficacy in the adoption and maintenance of health behaviours: Theoretical approaches and a new model'. in: Schwarzer, R. (ed.) *Self-efficacy: thought control of action.* Washington DC: Hemisphere Publishing Corp.217–38.

Scobbie, L., Dixon, D. & Wyke, S. (2011). 'Goal setting and action planning in the rehabilitation setting: development of a theoretically informed practice framework'. *Clinical Rehabilitation,* 25**,** 468-82.

Scobbie, L., Wyke, S. & Dixon, D. (2009). 'Identifying and applying psychological theory to setting and achieving rehabilitation goals'. *Clinical Rehabilitation,* 23**,** 321-33.

Seale, C. (1998). *Researching Culture and Society.* London: Sage.

Shenton, A. K. (2004). 'Strategies for ensuring trustworthiness in qualitative research projects'. *Education for Information,* 22**,** 63-75.

Silverman, D. (1998). 'Research and Social theory '. in: Seale, C. (ed.) *Researching Culture and Society.* London: Sage

Silverman, D. (2006). *Interpreting Qualitative Data: Methods for Analyzing Talk, Text and Interaction.* 3rd edn. London: Sage.

Silverman, D. (2013). *Doing Qualitative Research: A Practical Handbook.* 4th ed. London: Sage.

Skelton, J. (2016). 'Impact of Training'. in: Brown, J., Kidd, J., Noble, L*., et al.* (eds.) *Clinical Communication in Medicine.* Chichester: John Wiley & Sons.49-56.

Skidmore, E. R., Whyte, E. M., Holm, M. B., Becker, J. T., Butters, M. A., Dew, M. A., Munin, M. C. & Lenze, E. J. (2010). 'Cognitive and affective predictors of rehabilitation participation after stroke'. *Archives in Physical Medicine and Rehabilitation,* 91**,** 203-7.

Smith, R. (2006). 'Peer review: a flawed process at the heart of science and journals'. *Journal of the Royal Society of Medicine,* 99**,** 178-182.

Smith, V., Devane, D., Begley, C. & Clarke, M. (2011). 'Methodology in conducting a systematic review of systematic reviews of healthcare interventions'. *BMC Medical Research Methodology,* 11**,** 15.

Snyder, C. R. (2002). 'Hope Theory: Rainbows in the mind'. *Psychological Injury,* 13**,** 249-275.

Stewart, M. (2001). 'Towards a global definition of patient centred care'. *British Medical Journal,* 322**,** 444-445.

Strasser, D. C., Falconer, J. A., Herrin, J. S., Bowen, S. E., Stevens, A. B. & Uomoto, J. (2005). 'Team functioning and patient outcomes in stroke rehabilitation'. *Archives in Physical Medicine and Rehabilitation,* 86**,** 403-9.

Stroke Alliance for Europe (SAFE) (2007). 'The Burden of Stroke White paper-Raising awareness of the global toll of stroke related disability and death'. in: Charles, W. & Tony, R. (eds.). London: Stroke Alliance for Europe,

Stroke Association. (2013). *Feeling overwhelmed- The emotional impact of stroke.*London: Stroke Association.

Stroke Unit Trialists' Collaboration (1997). 'How Do Stroke Units Improve Patient Outcomes?: A Collaborative Systematic Review of the Randomized Trials'. *Stroke,* 28**,** 2139-2144.

Stroke Unit Trialists' Collaboration (2007). 'Organised inpatient (stroke unit) care for stroke'. *Cochrane Database Syst Rev***,** Cd000197.

Suddick, K. M. & De Souza, L. (2006). 'Therapists' experiences and perceptions of teamwork in neurological rehabilitation: reasoning behind the team approach, structure and composition of the team and teamworking processes'. *Physiotherapy Research International,* 11**,** 72-83.

Sugavanam, T., Mead, G., Bulley, C., Donaghy, M. & Wijck, F. (2012). 'The effects and experiences of goal setting in stroke rehabilitation ? a systematic review '. *Disability and Rehabilitation,* 35**,** 177-190.

Sulch, D., Perez, I., Melbourn, A. & Kalra, L. (2000). 'Randomized controlled trial of integrated (managed) care pathway for stroke rehabilitation'. *Stroke,* 31**,** 1929.

Teasdale, T. W. & Engberg, A. W. (2005). 'Psychosocial consequences of stroke: a long-term population-based follow-up'. *Brain Injury,* 19**,** 1049-58.

Tellier, M. & Rochette, A. (2009). 'Falling through the cracks: a literature review to understand the reality of mild stroke survivors'. *Topics in Stroke Rehabilitation,* 16**,** 454-62.

The Chartered Society of Physiotherapy (2010). *Developing a CSP vision for the future of UK physiotherapy.* London: The Chartered Society of Physiotherapy.

The Rt. Hon. Jeremy Hunt, M. (2015). *Making healthcare more human-centred and not system-centred* [Online]. King's Fund, London. Available:

https://www.gov.uk/government/speeches/making-healthcare-more-human-centred-and-not-system-centred [Accessed 01.12.15 2015].

Thomas, J. & Harden, A. (2008). 'Methods for the thematic synthesis of qualitative research in systematic reviews'. *BMC Medical Research Methodology,* 8**,** 1-10.

Thomas, J., Harden, A., Oakley, A., Oliver, S., Sutcliffe, K., Rees, R., Brunton, G. & Kavanagh, J. (2004). 'Integrating qualitative research with trials in systematic reviews'. *BMJ : British Medical Journal,* 328**,** 1010-1012.

Thomas, J., Sutcliffe, K., Harden, A., Oakley, A., Oliver, S., Rees, R., Brunton, G. & Kavanagh, J. (2003). *Children and Healthy Eating: A systematic review of barriers and facilitators.* London: EPPI-Centre, Social Science Research Unit, Institute of Education, University of London.

Timmermans, A. A. A., Seelen, H. A. M., Willmann, R. D., Bakx, W., de Ruyter, B., Lanfermann, G. & Kingma, H. (2009). 'Arm and hand skills: Training preferences after stroke'. *Disability and Rehabilitation,* 31**,** 1344-1352.

Tong, A., Sainsbury, P. & Craig, J. (2007). 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups'. *International Journal for Quality in Health Care,* 19**,** 349-357.

Turner-Stokes, L., Williams, H., Abraham, R. & Duckett, S. (2000). 'Clinical standards for inpatient specialist rehabilitation services in the UK'. *Clinical Rehabilitation,* 14**,** 468-480.

Van De Weyer, R. C., Ballinger, C. & Playford, E. D. (2010). 'Goal setting in neurological rehabilitation: staff perspectives'. *Disability and Rehabilitation,* 32**,** 1419-27.

Wade, D. T. (1999). 'Goal Planning in Stroke Rehabilitation: What?'. *Topics in Stroke Rehabilitation,* 6**,** 8-15.

Wade, D. T. (2009). 'Goal setting in rehabilitation: an overview of what, why and how'. *Clinical Rehabilitation,* 23**,** 291-5.

Wade, D. T. & de Jong, B. A. (2000). 'Recent advances: Recent advances in rehabilitation'. *British Medical Journal,* 320**,** 1385-1388.

Wagner, E. H., Austin, B. T., Davis, C., Hindmarsh, M., Schaefer, J. & Bonomi, A. (2001). 'Improving Chronic Illness Care: Translating Evidence Into Action'. *Health Affairs,* 20**,** 64-78.

Walker, E. & Dewar, B. J. (2000). 'Moving on from interpretivism: an argument for constructivist evaluation'. *Journal of Advanced Nursing,* 32**,** 713-720.

What works Network. (2014). *What works? evidence for decision makers.* [Online], Available: www.gov.uk/what-works-network [Accessed 01.12.15].

Williams, B. & Grant, G. (1998). 'Defining ‘people-centredness’: making the implicit explicit'. *Health and Social Care in the Community,* 6**,** 84-94.

World Federation of Occupational Therapists (WFOT). (2010). *Client-Centredness in Occupational Therapy.*Western Australia: WFOT.

World Health Organisation (WHO). (2002). *Towards a Common Language for Functioning,Disability and Health: ICF The International Classification of Functioning, Disability and Health.*Geneva: World Health Organisation (WHO).

World Health Organisation (WHO) (2006). 'Helsingborg Declaration 2006 on European Stroke Strategies'. in: Kjellström, T., Norrving, B. & Shatchkute, A. (eds.). Copenhagen: World Health Organization Regional Office for Europe

World Health Organisation (WHO) (2007). *People centred care: A Policy frame work.* Geneva: WHO press.

World Health Organization (WHO). (2011). *Global Atlas on cardiovascular disease prevention and control.*Geneva: World Health Organisation.

Wottrich, A. W., Stenstrom, C., Engardt, M., Tham, K. & Von Koch, L. (2004). 'Characteristics of physiotherapy sessions from the patient's and therapist's perspective'. *Disability and Rehabilitation,* 26**,** 1198.

Wressle, E., Eeg-Olofsson, A., Marcusson, J. & Henriksson, C. (2002). 'Improved client participation in the rehabilitation process using a client-centred goal formulation structure'. *Journal of Rehabilitation Medicine,* 34**,** 5-11.

Wressle, E., Oberg, B. & Henriksson, C. (1999). 'The rehabilitation process for the geriatric stroke patient--an exploratory study of goal setting and interventions'. *Disability and Rehabilitation,* 21**,** 80-7.

Wright, R. W., Brand, R. A., Dunn, W. & Spindler, K. P. (2007). 'How to write a systematic review'. *Clinical Orthopaedics and Related Research,* 455**,** 23-9.

Yin, R. K. (2003). *Case study Research Design and Methods.* 3rd ed. London: Sage.

Young, C. A., Manmathan, G. P. & Ward, J. C. (2008). 'Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff'. *Journal of Rehabilitation Medicine,* 40**,** 190-4.

Young, J. A. & Tolentino, M. (2009). 'Stroke evaluation and treatment'. *Topics in Stroke Rehabilitation,* 16**,** 389-410.

Young, R. A. & Collin, A. (2004). 'Introduction: Constructivism and social constructionism in the career field'. *Journal of Vocational Behavior,* 64**,** 373-388.

APPENDICES

Appendix 1.1 The purposes and mechanism of goal-setting in stroke rehabilitation

The literature in stroke was examined for typology for purposes and mechanisms for goal-setting. Levack *et al* (2006) had identified the different purposes and mechanisms referred to in goal-setting and categorised these purposes and mechanisms. These mechanisms have been related to the psychological theories to give them a theoretical grounding wherever possible (table 1.1).

Appendix 1.1 Purposes, Mechanism of action, related theory with examples of goal-setting studies in stroke.

Purpose of Goal-setting	**Mechanism of action if described**	**Theoretical basis** (Rosewilliam, Pandyan and Roskell, 2014).	**Evidence in stroke**
To improve patient outcomes	This could happen in 4 ways Patient's level of motivation can be improved by working on goal commitment and task complexity and hence result in better performance of tasks Setting specific and slightly challenging goals can result in higher effort and hence result in better performance. Goals that focus on tasks meaningful to the patient can increase motivation and goal commitment. If these goals identify specific contexts and tasks followed on by active practice this can lead to improved outcomes.	Locke and Latham's Goal setting theory Motor control theory and Locke and Latham's goal-setting theory; goal importance theory.	Gauggel, Leinberger and Richardt, (2001) found that patients who had specific and high goals responded faster at a computer task than patients with 'do your best goal'. Gauggel, Hoop and Werner, (2002) found that assigned difficult goals resulted in better performance in arithmetic tasks compared to self-set goals (which were less difficult) and 'do your best goals'. Ponte-Allan and Giles, (1999) found that patients with CVA who had made functional, independence focussed goals (personally meaningful goals) had significantly better functional outcomes that those who had not made focussed goal statements. A review of goal-setting in rehabilitation revealed that goal setting could improve adherence to treatment and improve immediate treatment

	Goals for secondary therapeutic purposes by patients developing better psychological adaptation to illness or disability. The process of goal-setting enables clinicians to negotiate what is possible compared to what is desirable. This helps patients in two ways: to help them cope with loss of life goals, become aware of strategies recommended for them whereby they can maintain strategies own their own. Secondary psychological effects can result from patients' knowledge of goals which gives them a better control over the situation.	Locus of control theory	effects if goals were specific and slightly challenging (Levack *et al.*, 2006). The latter was a finding from high quality studies that involved stroke patients along with other brain injury patients; however this review does not describe any specific methods of goal-setting that can be used in a stroke rehabilitation setup. Patients who had functional goals that were personally preferred such as drinking their favourite drink compared who patients who took the cup to the mouth with no drink were found to have better movement and reaction time in the use of the upper limb (Wu *et al.*, 2001). Use of life goals is suggested to help patients develop realistic expectations and coping with loss of life goals. It can further help them to relate their treatment goals towards their life goals (Nair and Wade, 2003). McGrath and Adams, (1999) found that self-reported fear and anxiety were reduced following participation in goal-setting process where the Rivermead life goals questionnaire was used to identify patients' own life goals. Holliday *et al.*, (2007b) reported improved psychological well- being following increased

	Goal-setting process itself can improve communication amongst staff, improve decision making based on collaborative problem solving and also direct better efforts towards patient's rehabilitation. Staff have also reported to be satisfied with setting goals which can feed into motivation at work.		participation in goal-setting compared to patients who did not. These patients also felt more satisfied with their rehabilitation care if they had increased participation in goal-setting. Therapists reported that working together in a goal-setting context as a team enabled joint working towards patients' goals by sharing professional skills and ideas (Suddick and De Souza, 2006). Professionals were satisfied with their participation, behaviour of others, process and outcomes which showed cohesive working within team meetings (Nair and Wade, 2003). Professionals who participated in a workshop that explored their perceptions of goal-setting suggested that it improves multidisciplinary work by improving communication, working coherently and being productive (Playford *et al.*, 2000).
To improve patient autonomy	Awareness about strategies discussed during goal-setting can empower and enable decisional and executional autonomy. They are more involved and take ownership of goal achievement.		The use of a structured tool (COPM) to identify aims for rehabilitation with patients made them perceive that they had identified treatment goals as active participants, were better at recalling goals and were able to manage better after completing rehabilitation compared to the control group who did not use this tool (Wressle *et al.*, 2002).

To evaluate rehabilitation outcomes	Comparing achievement of goals prior to rehabilitation and after rehabilitation. Objective measures such as GAS and subjective measures such as COPM have been used for this.		Community therapists reported that they evaluated the success of their therapy by measuring the attainment of goals set collaboratively with patients (Hale and Piggot, 2005). A nationwide survey identified that goal-setting was used by approximately 30% of respondents as an outcome measure of effectiveness of rehabilitation (Holliday, Antoun and Playford, 2005). GAS was shown to be a responsive outcome measure in patients with complex disabilities following stroke rather than the routine functional outcome measures. Use of GAS captured goal achievement of 74% of personal goals that had been set (Turner-Stokes, Williams and Johnson, 2009). Patients identified goals using COPM at the point of admission and self-perceived satisfaction and performance at discharge. Use of COPM revealed significant improvement in participation and satisfaction at point of discharge (Phipps and Richardson, 2007).
To meet contractual, legislative or professional requirements	Documenting goals in case notes is evidence for healthcare processes. Goals set with the patients and carers is considered as a good quality practice and decision making strategy.		Intercollegiate Stroke Working Party, (2012); Royal College of Physicians (RCP), (2015)

It is clear from the table 1.1 that different mechanisms serve different purposes of goal-setting. These variations in goal-setting mechanisms can explain the use of many different approaches and methods of goal-setting seen in the different contexts of stroke rehabilitation. In some cases the way in which a particular approach to goal-setting worked might be conflicting for a different purpose. For example when goal-setting was modelled to improve cohesive team-working, the same cohesiveness within the team might have isolated the patient especially if they were not involved in the process (Suddick and De Souza, 2006). This understanding of the mechanisms is pertinent for this work which was set out to examine goal-setting practice.

References

Gauggel, S., Hoop, M. & Werner, K. (2002). 'Assigned versus self-set goals and their impact on the performance of brain-damaged patients'. *Journal of Clinical and Experimental Neuropsychology,* 24**,** 1070-80.

Gauggel, S., Leinberger, R. & Richardt, M. (2001). 'Goal setting and reaction time performance in brain-damaged patients'. *Journal of Clinical and Experimental Neuropsychology,* 23**,** 351-61.

Hale, L. A. & Piggot, J. (2005). 'Exploring the content of physiotherapeutic home-based stroke rehabilitation in New Zealand'. *Archives of Physical Medicine and Rehabilitation,* 86**,** 1933-1940.

Holliday, R. C., Antoun, M. & Playford, E. D. (2005). 'A Survey of Goal-Setting Methods Used in Rehabilitation'. *Neurorehabilitation and Neural Repair,* 19**,** 227-231.

Holliday, R. C., Cano, S., Freeman, J. A. & Playford, E. D. (2007b). 'Should patients participate in clinical decision making? An optimised balance block design controlled study of goal setting in a rehabilitation unit'. *Journal of Neurology, Neurosurgery, and Psychiatry,* 78**,** 576-580.

Intercollegiate Stroke Working Party. (2012). *National clinical guidelines for stroke (4th ed).*London: Royal College of Physicians.

Levack, W. M. M., Dean, S. G., Siegert, R. J. & McPherson, K. M. (2006). 'Purposes and mechanisms of goal planning in rehabilitation: the need for a critical distinction'. *Disability and Rehabilitation,* 28**,** 741-9.

McGrath, J. R. & Adams, L. (1999). 'Patient-centered goal planning: a systemic psychological therapy?'. *Topics in Stroke Rehabilitation,* 6**,** 43-50.

Nair, K. P. & Wade, D. T. (2003). 'Satisfaction of members of interdisciplinary rehabilitation teams with goal planning meetings'. *Archives of Physical Medicine and Rehabilitation,* 84**,** 1710-3.

Phipps, S. & Richardson, P. (2007). 'Occupational therapy outcomes for clients with traumatic brain injury and stroke using the Canadian Occupational Performance Measure'. *American Journal of Occupational Therapy,* 61**,** 328-34.

Playford, E. D., Dawson, L., Limbert, V., Smith, M., Ward, C. D. & Wells, R. (2000). 'Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting'. *Clinical Rehabilitation,* 14**,** 491-496.

Ponte-Allan, M. & Giles, G. M. (1999). 'Goal Setting and Functional Outcomes in Rehabilitation'. *American Journal of Occupational Therapy,* 53**,** 646-649.

Rosewilliam, S., Pandyan, A. D. & Roskell, C. A. (2014). 'Goal Setting in Stroke Rehabilitation: Theory, Practice and Future Directions'. *Rehabilitation Goal Setting.* CRC Press.345-370.

Royal College of Physicians (RCP). (2015). *Sentinel Stroke National Audit Programme (SSNAP)* [Online]. Available: https://www.rcplondon.ac.uk/projects/outputs/sentinel-stroke-national-audit-programme-ssnap [Accessed 16.03.15 2015].

Suddick, K. M. & De Souza, L. (2006). 'Therapists' experiences and perceptions of teamwork in neurological rehabilitation: reasoning behind the team approach, structure and composition of the team and teamworking processes'. *Physiotherapy Research International,* 11**,** 72-83.

Turner-Stokes, L., Williams, H. & Johnson, J. (2009). 'Goal attainment scaling: Does it provide added value as a person-centred measure for evaluation of outcome in neurorehabilitation following acquired brain injury?'. *Journal of Rehabilitation Medicine,* 41**,** 528.

Wressle, E., Eeg-Olofsson, A. M., Marcusson, J. & Henriksson, C. (2002). 'Improved client participation in the rehabilitation process using a client-centred goal formulation structure'. *J REHABIL MED,* 34**,** 5-11.

Wu, C., Wong, M., Lin, K. & Chen, H. (2001). 'Effects of Task Goal and Personal Preference on Seated Reaching Kinematics After Stroke'. *Stroke,* 32**,** 70-76.

Appendix 2.1 Details of the electronic databases searched with Search Topics, Numbers and Results

Details of the electronic databases searched with Search Topics, Numbers and Results										
No.	**Provider**	**Database**	**Patient Centred & related terms (using OR) #40**	**Stroke & related terms (using OR) #47**	**Goals & related terms (using OR) #53**	**Patient Centred & Stroke (using AND) #40 & #47**	**Patient Centred & Goals (using AND) # 40 & #53**	**Stroke & Goals (using AND) #47 & #53**	**Patient Centred & Stroke & Goals (using AND) #40 & #47 & #53**	**Limiters**
	EBSCO	AMED	2357	5335	4351	201	202	249	21 Screening based on abstra	Published Date: 19800101-20141231 Language: ENGLISH

									cts	
									15 added to folder & endnote	Based on screening of titles, keywords and abstract
		When searched with quotation marks there are less results compared to when searched with brackets. Help on site recommends quotation marks. Hence done with quotation marks.								
	EBSCO	CINAHL (Plus)	8996	28561	18388	160	517	442	30	Limiters - Published Date: 19800101-20141231; English Language; Human
									25 added to folder	Based on screening of titles, keywords and abstract
	EBSCO	Sport	2557	12437	27684	176	141	277	17	Limiters -

		Discus								Published Date: 19800101-20141231; Language: English
									13 to folder	
	WILEYS	Cochrane	160154	38729	4822	7435	2415	448	354	YR1980- YR 2014 Limiters- Abstract; Word variations searched.
									27 added to folder	
	Thomson & Reuter	Science Citation	387154	202864	254393	13670	9941	3735	490	LANGUAGE: (English)

		Index Expanded								Indexes=SCI-EXPANDED Timespan=1980-2014
									47 added to folder	
			Only 40 lines of search history can be saved in this database. Others saved a scree shot for record.							
	No abstract field search here Modified within search for English language. So instead of creating new sets which extends up to search 44, I decided to overwrite existing search during the refinement step.									
		ProQuest	793637	288610	1235413	18628	24625	6934	711	Month Jan YR 1980-Month Nov YR 2014
	NOT (MEDLINE® AND ABI/INFORM Trade & Industry AND TOXLINE AND ProQuest Deep Indexing: Biological Sciences AND Mechanical & Transportation Engineering Abstracts AND Computer and Information Systems Abstracts AND ProQuest Deep Indexing: Technology AND ABI/INFORM Global AND Electronics & Communications Abstracts AND Computer and Information Systems Abstracts AND ProQuest Deep Indexing: Engineering AND ERIC AND Biotechnology and BioEngineering Abstracts AND Linguistics and Language Behavior Abstracts									ab(…) AND la.exact("English") Month Jan YR 1980-Month Dec YR 2014

	(LLBA) AND Aerospace Database AND Biotechnology Research Abstracts AND Toxicology Abstracts AND ProQuest Deep Indexing: Advanced Technologies AND Abstracts in New Technology & Engineering AND Solid State and Superconductivity Abstracts AND ProQuest Deep Indexing: Aquatic Sciences AND ProQuest Deep Indexing: Computer Science AND Immunology Abstracts AND ProQuest Dissertations & Theses Global: Business AND Materials Research Database AND Bacteriology Abstracts (Microbiology B) AND Risk Abstracts AND Sustainability Science Abstracts AND ProQuest Deep Indexing: Materials Science AND Genetics Abstracts AND Calcium & Calcified Tissue Abstracts AND Virology and AIDS Abstracts AND Water Resources Abstracts AND Industrial and Applied Microbiology Abstracts (Microbiology A) AND Algology Mycology and Protozoology Abstracts (Microbiology C)									
									Reduced to 240 after ruling out the above databases; 35 adde	

									d to folde r	
		PC #79	Stroke #92	Goal-setting #103	PC in Stroke #79 and #92	PC Goal-setting #79 and #103	Stroke And Goal setting #92 and # 103	PC in Stroke In GS #79 and #92 and #103		
	OVID	Medline	17349	141379	51747	205	890	1007	39	Month YR 1980-Month YR 2014
										[mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word,

										rare disease supplementary concept word, unique identifier] Limit to (english language and humans and yr="1980 - 2014")
									28 sent to folder and end note	
	OVID	Psych Info	8540	20239	62447	90	593	281	20	Month YR 1980-Month YR 2014
									17 sent to	[mp=title, abstract, heading word,

									folder and end note	table of contents, key concepts, original title, tests & measures] Limit to (human and english language and yr="1980 - 2014")
									106 after duplicates removed	

Appendix 2.2 Results from screening of abstracts collected from the electronic search by reviewers.

Results from screening of abstracts collected from the electronic search by reviewers.			
Reasons	SR	AS	Decision made
Trial Registry	1	1	
Thesis	5	5	To look for relevant publications
Thesis+ No PCGS	1	1	
Expert opinion + No PCGS	1	1	
Review Protocol	1	1	To look for relevant publications
No stroke patients	1	1	
No adult patients	1	1	
Conference abstract	9	9	To look for relevant publications
No PCGS	21	21	
Total Rejected	41	41	
Unsure /taken to next stage	6	1 (Playford 1997)	To screen full text of these 7 articles
Sure	58		To screen full text of these
Therefore total number of articles to screen from primary search is 58+6+1= 65			
Screening of References from Secondary Search			

Total numbers in the list of references from secondary search **81**			
References after the removal of Duplicates **61**			
References after removal of references covered in E-search **48**			
Screening of Abstracts from Secondary Search			
Reasons	SR	AS	Decision made
Did not have one or more of the concepts	6	13	
No stroke patients	2	3	
Expert opinion	1	1	
Theoretical paper	1	1	
Review		2	
Total Rejected	10	21	Discuss differences
Unsure /Taken to next stage	**22**	14	Discuss differences and read full text
Sure	16	13	Read full text
Overall numbers taken to next stage following discussion	Definite rejects 11 Unsure/ take to next stage 22 Sure 15		
Therefore total number of articles to screen from secondary search is 22+ 15= 37			

Appendix 2.3 Articles rejected after screening of full texts from electronic search with reasons and full references

(Aziz Noor *et al.*, 2008)	Review does not look at PC or GS. None of the studies that have implemented goal-setting or patient-centred principles during process were included in review.
(Bower *et al.*, 2012)	The aim of the study was to investigate the impact of occupational therapists' and physiotherapists' standard practice on clients' and carers' self-management of upper limb recovery. The goals were prescribed to patients by therapists using GAS.
(Brashler, 2006)	Expert opinion which advocates family focused goals and treatment.
(Buck *et al.*, 2000)	Review of measures of quality of life after stroke. Did not study setting goals or examine patient-centredness in QOL measures. Authors conclude QOL measures were not developed using a patient-centred approach as all pertinent issues were not covered by any QOL measures.
(Cheeran *et al.*, 2009)	The consensus group discusses translation of research into practice. No goal-setting studies considered.
(Cott and Finch, 2007)	This is an invited commentary on the Movement continuum theory (MCT). Authors analyse the theory and suggest MCT has the potential to incorporate client perspectives when deciding movement goals.
(Demetrios *et al.*, 2013)	The systematic review looked at MDT therapy following botox injections. None of the studies included used client-centred goal-setting for the therapies delivered.
(Duff, 2009)	This is an expert opinion of goal-setting process highlighting needs assessment checklist tool and applying it in a case study.
(Donnellan and O'Neill,	This article proposes a theoretical framework for stroke rehabilitation based on Baltes'

2014)	SOC model of development of adults as they progress through life-span. The model refers to the selection, optimisation, and compensation of one's goals in response to changes with ageing. However this article does not evaluate its proposals or even suggest strategies as how to apply this model in goal-setting practice. Hence article not included in review.
(Ellis *et al.*, 2010)	Stroke liaison workers for stroke patients and carers: an individual patient data meta-analysis. 1) These workers did not do goal-setting
(Fletcher-Smith Joanna *et al.*, 2013)	Occupational therapy for care home residents with stroke. Review of OT interventions found one study. 1) This study did not include goal-setting 2) It did not consider patient-centredness
(Graven *et al.*, 2011)	This is a detailed protocol for a study. Not completed. To look for studies by this author.
(Holloway *et al.*, 2014)	Expert opinions/Practice guidelines based on different literature. Not a specific study.
(Hunt and Ells, 2011)	This paper is a theoretical analysis of risk and relational autonomy relevant to rehabilitation care. Does not discuss goal setting. Hence exclude.
(Koch, Wottrich and Holmqvist, 1998)	The study aimed to study interaction between therapist and patients in two situations hospital and home. Three patient therapist interactions were studied using observations, interviews and documents. Goal setting was not studied or person-centered approach was not applied in this study. However it was found that in the home context patient took initiative and expressed goals relevant to his daily life whereas in the hospital patients did not volunteer goals. Since the intention of the study was not to study goal-setting involving person centeredness there is not much information about the process or concept. Hence reject.
(Kristensen *et al.*, 2011)	The aim of the review was not to study goal-setting but when looking for client-centred

	studies found a few that involved goal-setting. Descriptive presentation of findings does not give any new insights. Hence decided to look at the included studies for relevance in the secondary search.
(Levine *et al.*, 2000)	The study describes the application of Goal management training in two cases in patients with TBI and postencephalitis.
(McCrory *et al.*, 2009)	The aim of the study was to investigate the benefits of Botox injection on the UL. They investigated certain outcomes such as pain, mood and GAS and classified these outcome measures as patient-centred outcomes. There was in adequate justification as to why these outcomes were classified as patient centred outcomes and insufficient information as to what principles of patient-centredness were applied in setting goals. Hence reject.
(McKellar *et al.*, 2011)	The aim of the study was to investigate the effects of interprofessional learning for health workers to integrate competencies for IPC and community re-engagement work. The study did not aim to improve PCGS or discuss any form of GS for patients. But one finding was that patient-centred goal-setting improved with no further details regarding this claim. Hence reject.
(MacDonald, Kayes and Bright, 2013)	This review looked at studies that discussed facilitators and barriers for engagement for rehabilitation. It did not find any studies that specifically examined engagement, hence looked at studies that looked at experiences of rehabilitation that discussed factors related to engagement. Goal-setting and patient focussed care were identified as motivating factors and hence facilitators for engagement. Since these studies did not study engagement but identified other factors that could link to engagement, it was decided not to include this review. However the references in the review will be looked

	at for any relevance.
(Mudge, Stretton and Kayes, 2014)	The aim of the study is understand conflicting responses and responses to person centered rehabilitation within physiotherapy practice by reflecting on own practice, experiences as research and clinical therapists. The two physios reflect on why their practice is not patient-centred, their dilemmas especially related to setting goals. However their reflections are related to their neuro practices and with no special considerations related to stroke care. Hence to leave out for the review.
(Phipps and Richardson, 2007)	Was included in the publication. The aim of the study is determine whether a client-centered goal setting approach was related to improved performance and satisfaction. The authors of COPM claim that COPM is a patient-centred goal-setting tool. So does that mean all COPM studies should be reviewed? (*My review is not about COPM. But about studies that claim the application of patient-centred mechanisms for setting goals*) There are other studies that use COPM to identify goals and show that performance and satisfaction improve. Why include this study alone? (*search identified, fulfils criteria*)
(Playford *et al.*, 1997)	Integrated care pathways: evaluating inpatient rehabilitation in stroke. Does not involve patient-centred principles.
(Prigatano and Wong, 1999)	This study looks at whether improvements in specific cognitive and affective functions are associated with achieving inpatient rehabilitation goals after the acute onset of brain dysfunction. Goals were set by the treating team and physician. No aspect of patient-centredness

	identified.
(Redfern, McKevitt and Wolfe, 2006)	This study aims to investigate the delivery of strategies to manage the risk of stroke recurrence in the context of the stroke clinic, a forum for providing clinical follow up for patients after stroke. No discussion of goals set or the process of setting goals.
(Rees, Wilcox and Cuddihy, 2002)	This is a clinical review that looks at how psychologists and psychological theories can influence rehabilitation. Discusses patient-centred goal setting and role of psychologists to inform this process.
(Rosewilliam, Roskell and Pandyan, 2011)	Previous review – to include studies and build on it.
(Shepperd *et al.*, 2013)	This review looks at discharge planning effectiveness on various outcomes. DP is defined as planning prior to patients leaving the hospital. One study within it involved stroke patients and studied integrated care pathway.
(Siegert *et al.*, 2007)	Discusses Good Lives model as a framework for rehabilitation. Does not involve goal-setting for patients with stroke. Hence reject.
(Sunnerhagen and Francisco, 2013)	This paper is an expert opinion that analyses gap in communication between parties in the management of spasticity following stroke. Recommends the use of GAS for client-centred goal-setting for management of stroke.
(Turner-Stokes *et al.*, 2013)	Data repeated from Turner-Stokes 2010, Hence reject.
(Turner-Stokes, Williams and Johnson, 2009)	To compare goal attainment scaling (GAS) and standardized measures in evaluation of person-centred outcomes in neurorehabilitation. FIM+FAM are functional outcome measures. Hence they can only measure functional goals. GAS is open ended outcome measure that can fit in any aspect of patient goals. Hence deemed patient-centred. This study is rejected the process of GS is not discussed and hence PC is only suggestive

	based on use of GAS.
(Wade, 1999a)	Expert opinion based on clinical review. To look at reference list.
(Wei, Barr and George, 2014)	To explore what the obstacles are that deter patients from continuing stroke rehabilitation after discharge from hospital in Singapore. Individual semi-structured telephone interviews were undertaken and analysed using inductive thematic analysis for thirty one stroke patients. Goal-setting was not discussed in any of the themes as cause for non-compliance with rehab.
(Woodman *et al.*, 2014)	The aim of this review is identify, appraise and synthesise qualitative research on stroke survivors' experiences of social participation. Does not report on aspects of goal-setting in this review. However authors recommend collaborative GS could take into consideration the issues with participation identified in this review. Hence reject
(Yagura *et al.*, 2005)	Studied outcomes in patients admitted to two types of stroke care. One had weekly inter-disciplinary meetings discussing goals. However these meetings were not collaborative with patients or families. No PCGS.
(OutpatientServiceTrialists., 2003)	No information on how PCC is included in GS

Articles from secondary search rejected after screening of full texts with reasons

(Conneeley, 2004)	Conneeley (2004)	No mention of involving stroke patients in study
(Dixon, Thornton and Young, 2007)	Dixon G, Thornton EW and Young CA.(2007)	Goal-setting was perceived to contribute to self-efficacy beliefs in this study where stroke patients were included. However the data to support the above was not from stroke patients.
(Gagne and Hoppes, 2003)	Gagné DE, Hoppes S.	No stroke patients specified.
(Gilbertson *et al.*, 2000)	Gilbertson L, Langhorne P, Walker A, Allen A and Murray GD.	States therapy was delivered to patients tailored to their recovery goals. No information on how goals were set, measured or documented.
(Lavelle and Tomlin, 2001)	Lavelle P, Tomlin GS	Did not study collaborative GS
(McEwen *et al.*, 2009)	McEwen SE, Helene J. Polatajko, Jane A. Davis, Maria Huijbregts, and Jennifer D. Ryan	The study explored experiences with CO-OP not the goal-setting in CO-OP.
(McMillan and Sparkes, 1999)	McMillan TM, Sparkes C	Does not fit the client-centred criteria.
(Mew and Fossey, 1996)	Mew MM, Fossey E.	Not related to GS or stroke.
(Resnick, 2002)	Resnick B (2002)	Study done in orthopaedic patients.
(Stephenson and Wiles, 2000)	Stephenson S	Therapists had suggested their GS was client-centred with no details of how it was done.

Articles rejected during stage of data abstraction with reasons for rejection

(Andreassen and Wyller, 2005)	Goals were not set for rehabilitation but they were asked what they wanted from the program. It was mostly filled in by others for the patient and professionals were not exploring the reason for self-referral but researchers were.
(Broetz and Birbaumer, 2013)	Behavioural physiotherapy included patient-centred goals were worked on. Does not state delivery method and was the patient asked for his goals? Who asked? It states patient aimed to reduce knee pain and improve motor control. No information on the setting or review of goals from the patient's perspective.
(Foye *et al.*,2002)	Does not include stroke, author suggest that this information can be extrapolated to professionals.
(Donnellan *et al.*, 2013)	This study explored experiences of stroke patients and identified coping and goals of patients. There is nothing to do with goal-setting process specifically. Generic suggestion of patients must be involved in decision making about care.
(Harris and Eng, 2004)	Investigated goals using COPM and listed goals of chronic stroke patients. Neither the aim or the results tell us how why they think COPM is a patient-centred method.
(Roberts *et al.*, 2005)	Though the study aim is to see if CIT for activities meaningful for the patient was effective, the research does not explain how these meaningful activities were chosen, i.e how goals were set.
(Turner-Stokes *et al.*, 2010)	This is an interventional study where 2 personal goals were set for each patient along with therapists. GAS was used to grade these. Made a list of what goals were chosen. Botox was given but not pertinent to these goals. Unable to see the link between setting personal goals and achievement of goals and botox. Whether other goals that were not personal improved is not clear. So botox can improve function whether one sets personal goals are not.
(Hersh *et al.*, 2012b)	This article is a conceptual framework proposed by the authors based on their work and based on literature. This is a proposal that has not been tested and does not describe any particular study. Hence classified as expert opinion based on evidence and not included in the review.

References

Andreassen, S. & Wyller, T. B. (2005). 'Patients' experiences with self-referral to in-patient rehabilitation: A qualitative interview study'. *Disability and Rehabilitation,* 27**,** 1307-1313.

Aziz Noor, A., Leonardi-Bee, J., Phillips Margaret, F., Gladman, J., Legg Lynn, A. & Walker, M. (2008). Therapy-based rehabilitation services for patients living at home more than one year after stroke. *Cochrane Database of Systematic Reviews* [Online]. Available.

Bower, K., Gustafsson, L., Hoffmann, T. & Barker, R. (2012). 'Self-management of upper limb recovery after stroke: how effectively do occupational therapists and physiotherapists train clients and carers?'. *British Journal of Occupational Therapy,* 75**,** 180-187.

Brashler, R. (2006). 'Ethics, family caregivers, and stroke'. *Topics in Stroke Rehabilitation,* 13**,** 11-17.

Broetz, D. & Birbaumer, N. (2013). 'Behavioral physiotherapy in post stroke rehabilitation'. *Neurorehabilitation,* 33**,** 377.

Buck, D., Jacoby, A., Massey, A. & Ford, G. (2000). 'Evaluation of measures used to assess quality of life after stroke'. *Stroke,* 31**,** 2004.

Cheeran, B., Cohen, L., Dobkin, B., Ford, G., Greenwood, R., Howard, D., Husain, M., Macleod, M., Nudo, R., Rothwell, J., Rudd, A., Teo, J., Ward, N., Wolf, S. & Cumberland Consensus Working, G. (2009). 'The Future of Restorative Neurosciences in Stroke: Driving the Translational Research Pipeline From Basic Science to Rehabilitation of People After Stroke'. *Neurorehabilitation and Neural Repair,* 23**,** 97-107.

Conneeley, A. L. (2004). 'Interdisciplinary Collaborative Goal Planning in a Post-Acute Neurological Setting: a Qualitative Study'. *British Journal of Occupational Therapy,* 67**,** 248.

Cott, C. A. & Finch, E. (2007). 'Invited Commentary: Cheryl A Cott, Elspeth Finch'. *Physical Therapy,* 87**,** 925-926.

Demetrios, M., Khan, F., Turner-Stokes, L., Brand, C. & McSweeney,

S.(2013) Multidisciplinary rehabilitation following botulinum toxin and other focal intramuscular treatment for post-stroke spasticity *Cochrane Database of Systematic Reviews* Issue 6. Cd009689

Dixon, G., Thornton, E. W. & Young, C. A. (2007). 'Perceptions of self-efficacy and rehabilitation among neurologically disabled adults'. *Clinical Rehabilitation,* 21**,** 230-240.

Donnellan, C., Martins, A., Conlon, A., Coughlan, T., O'Neill, D. & Collins, D. R. (2013). 'Mapping patients' experiences after stroke onto a patient-focused intervention framework'. *Disability & Rehabilitation,* 35**,** 483-491.

Donnellan, C. & O'Neill, D. (2014). 'Baltes' SOC model of successful ageing as a potential framework for stroke rehabilitation'. *Disability & Rehabilitation,* 36**,** 424-9.

Duff, J. (2009). 'Team Assessment in Stroke Rehabilitation'. *Topics in Stroke Rehabilitation,* 16**,** 411-419.

Ellis, G., Mant, J., Langhorne, P., Dennis, M. & Winner, S. (2010). Stroke liaison workers for stroke patients and carers: an individual patient data meta-analysis. *Cochrane Database of Systematic Reviews* [Online]. Available.

Fletcher-Smith Joanna, C., Walker Marion, F., Cobley Christine, S., Steultjens Esther, M. J. & Sackley Catherine, M. (2013). Occupational therapy for care home residents with stroke. *Cochrane Database of Systematic Reviews* [Online]. Available.

Foye, S. J., Kirschner, K. L., Wagner, L. C. B., Stocking, C. & Siegler, M. (2002). 'Ethics in practice. Ethical issues in rehabilitation: a qualitative analysis of dilemmas identified by occupational therapists'. *Topics in Stroke Rehabilitation,* 9**,** 89-101.

Gagne, D. E. & Hoppes, S. (2003). 'The effects of collaborative goal-focused occupational therapy on self-care skills: a pilot study'. *Am J Occup Ther,* 57**,** 215-9.

Gilbertson, L., Langhorne, P., Walker, A., Allen, A. & Murray, G. D. (2000). 'Domiciliary occupational therapy for patients with stroke discharged from

hospital: randomised controlled trial'. *Bmj,* 320**,** 603-6.

Graven, C., Brock, K., Hill, K., Ames, D., Cotton, S. & Joubert, L. (2011). 'From rehabilitation to recovery: protocol for a randomised controlled trial evaluating a goal-based intervention to reduce depression and facilitate participation post-stroke'. *BMC Neurology,* 11**,** 73.

Harris, J. E. & Eng, J. J. (2004). 'Goal Priorities Identified through Client-Centred Measurement in Individuals with Chronic Stroke'. *Physiotherapy Canada,* 56**,** 171.

Hersh, D., Worrall, L., Howe, T., Sherratt, S. & Davidson, B. (2012b). 'SMARTER goal setting in aphasia rehabilitation'. *Aphasiology,* 26**,** 220-233.

Holloway, R. G., Arnold, R. M., Creutzfeldt, C. J., Lewis, E. F., Lutz, B. J., McCann, R. M., Rabinstein, A. A., Saposnik, G., Sheth, K. N., Zahuranec, D. B., Zipfel, G. J. & Zorowitz, R. D. (2014). 'Palliative and End-of-Life Care in Stroke:A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association'. *Stroke (00392499),* 45**,** 1887-1916.

Hunt, M. R. & Ells, C. (2011). 'Partners towards autonomy: risky choices and relational autonomy in rehabilitation care'. *Disability & Rehabilitation,* 33**,** 961-7.

Koch, L., Wottrich, A. W. & Holmqvist, L. W. (1998). Rehabilitation in the home versus the hospital: the importance of context. *Disability and Rehabilitation* [Online], 20. Available.

Kristensen, H. K., Persson, D., Nygren, C., Boll, M. & Matzen, P. (2011). 'Evaluation of evidence within occupational therapy in stroke rehabilitation'. *Scandinavian Journal of Occupational Therapy,* 18**,** 11-25.

Lavelle, P. & Tomlin, G. S. (2001).'Occupational Therapy Goal Achievement for Persons With Postacute Cerebrovascular Accident in an On-Campus Student Clinic'. *American Journal of Occupational Therapy,* 55**,** 36-42.

Levine, B., Robertson, I. H., Clare, L., Carter, G., Hong, J., Wilson, B. A., Duncan, J. & Stuss, D. T. (2000). Rehabilitation of executive functioning: an

experimental-clinical validation of goal management training. *Journal of the International Neuropsychological Society : JINS* [Online], 6. Available.

MacDonald, G. A., Kayes, N. M. & Bright, F. (2013). 'Barriers and facilitators to engagement in rehabilitation for people with stroke: A review of the literature'. *N Z J PHYSIOTHER,* 41**,** 112.

McCrory, P., Turner-Stokes, L., Baguley, I. J., De Graaff, S., Katrak, P., Sandanam, J., Davies, L., Munns, M. & Hughes, A. (2009). 'Botulinum toxin A for treatment of upper limb spasticity following stroke: a multi-centre randomized placebo-controlled study of the effects on quality of life and other person-centred outcomes'. *Journal of Rehabilitation Medicine (Stiftelsen Rehabiliteringsinformation),* 41**,** 536-544.

McEwen, S. E., Polatajko, H. J., Huijbregts, M. P. & Ryan, J. D. (2009). 'Exploring a cognitive-based treatment approach to improve motor-based skill performance in chronic stroke: Results of three single case experiments'. *Brain Injury,* 23**,** 1041-1053.

McKellar, J. M., Cheung, D., Lowe, M., Willems, J., Heus, L. & Parsons, J. (2011). 'Healthcare providers' perspectives on an interprofessional education intervention for promoting community re-engagement post stroke'. *Journal of Interprofessional Care,* 25**,** 380-382.

McMillan, T. M. & Sparkes, C. (1999). 'Goal planning and neurorehabilitation: The Wolfson Neurorehabilitation Centre approach'. *Neuropsychological Rehabilitation,* 9**,** 241-251.

Mew, M. M. & Fossey, E. (1996). 'Client-centred aspects of clinical reasoning during an initial assessment using the Canadian Occupational Performance Measure'. *Australian Occupational Therapy Journal,* 43**,** 155-166.

Mudge, S., Stretton, C. & Kayes, N. (2014). 'Are physiotherapists comfortable with person-centred practice? An autoethnographic insight'. *Disability and Rehabilitation,* 36**,** 457-463.

OutpatientServiceTrialists. (2003). Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database of Systematic Reviews* [Online].

Phipps, S. & Richardson, P. (2007). 'Occupational Therapy Outcomes for Clients With Traumatic Brain Injury and Stroke Using the Canadian Occupational Performance Measure'. *AMERICAN JOURNAL OF OCCUPATIONAL THERAPY,* 61**,** 328.

Playford, E. D., Rossiter, D., Werring, D. J. & Thompson, A. J. (1997). 'Integrated care pathways: evaluating inpatient rehabilitation in stroke'. *British Journal of Therapy and Rehabilitation,* 4**,** 97.

Prigatano, G. P. & Wong, J. L. (1999). 'Cognitive and affective improvement in brain dysfunctional patients who achieve inpatient rehabilitation goals'. *Archives of Physical Medicine and Rehabilitation,* 80**,** 77-84.

Redfern, J., McKevitt, C. & Wolfe, C. (2006). 'Risk management after stroke: the limits of a patient-centred approach'. *Health, Risk & Society,* 8**,** 123-141.

Rees, J., Wilcox, J. R. & Cuddihy, R. A. (2002). 'Psychology in rehabilitation of older adults'. *Reviews in Clinical Gerontology,* 12**,** 343-356.

Resnick, B. (2002). 'Geriatric Rehabilitation: The Influence of Efficacy Beliefs and Motivation'. *Rehabilitation Nursing,* 27**,** 152-159.

Roberts, P. S., Vegher, J. A., Gilewski, M., Bender, A. & Riggs, R. V. (2005). 'Client-Centered Occupational Therapy Using Constraint-Induced Therapy'. *Journal of Stroke and Cerebrovascular Diseases,* 14**,** 115-121.

Rosewilliam, S., Roskell, C. A. & Pandyan, A. D. (2011). 'A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation'. *Clinical Rehabilitation,* 25**,** 501-514.

Shepperd, S., Lannin Natasha, A., Clemson Lindy, M., McCluskey, A., Cameron Ian, D. & Barras Sarah, L. (2013). Discharge planning from hospital to home. *Cochrane Database of Systematic Reviews* [Online]. Available.

Siegert, R. J., Ward, T., Levack, W. M. M. & McPherson, K. M. (2007). 'A good lives model of clinical and community rehabilitation'. *Disability and Rehabilitation,* 29**,** 1604-1615.

Stephenson, S. & Wiles, R. (2000). 'Advantages and Disadvantages of the Home Setting for Therapy: Views of Patients and Therapists'. *The British Journal of Occupational Therapy,* 63**,** 59-64.

Sunnerhagen, K. & Francisco, G. (2013). 'Enhancing patient-provider communication for long-term post-stroke spasticity management'. *Acta Neurologica Scandinavica,* 128**,** 305-310.

Turner-Stokes, L., Baguley, I. J., De Graaff, S., Katrak, P., Davies, L., McCrory, P. & Hughes, A. (2010). 'Goal attainment scaling in the evaluation of treatment of upper limb spasticity with botulinum toxin: a secondary analysis from a double-blind placebo-controlled randomized clinical trial'. *Journal of Rehabilitation Medicine,* 42**,** 81-9.

Turner-Stokes, L., Fheodoroff, K., Jacinto, J. & Maisonobe, P. (2013). 'Results from the Upper Limb International Spasticity Study-II (ULIS-II): a large, international, prospective cohort study investigating practice and goal attainment following treatment with botulinum toxin A in real-life clinical management'. *British Medical Journal Open,* 3.

Turner-Stokes, L., Williams, H. & Johnson, J. (2009). 'Goal attainment scaling: Does it provide added value as a person-centred measure for evaluation of outcome in neurorehabilitation following acquired brain injury?'. *Journal of Rehabilitation Medicine,* 41**,** 528.

Wade, D. T. (1999). 'Goal planning in stroke rehabilitation: evidence'. *Topics in Stroke Rehabilitation,* 6**,** 37-42.

Wei, K., Barr, C. & George, S. (2014). 'Factors influencing post-stroke rehabilitation participation after discharge from hospital'. *International Journal of Therapy & Rehabilitation,* 21**,** 260-267.

Woodman, P., Riazi, A., Pereira, C. & Jones, F. (2014). 'Social participation post stroke: a meta-ethnographic review of the experiences and views of community-dwelling stroke survivors'. *Disability and Rehabilitation,* 36**,** 2031-2043.

Yagura, H., Miyai, I., Suzuki, T. & Yanagihara, T. (2005). Patients with severe stroke benefit most by interdisciplinary rehabilitation team approach (Structured abstract). *Cerebrovascular Diseases* [Online], 20.

Appendix 2.4. Data extraction table for quantitative studies included in the review [1]

Author, year and setting	Aims and Objectives	Study design and methods	Inclusion and exclusion criteria	Participant characteristics	Intervention and control details and Outcome measures	Analysis	Results
(Almborg *et al.*, 2008) Stroke unit Sweden	To describe patients' perception of participation in discussions about goals and needs for care, services and rehabilitation during discharge planning	Cross-sectional study. Patients were interviewed 2–3 weeks after discharge about their perception of their participation in discharg	Medical diagnosis of stroke, Able to speak Patients with severe aphasia, cognitive impairment and difficulties in understanding Swedish	N=188 Mean age 74 yrs. 105 Men and 83 women 59% lived with someone. 41% lived alone. 93% had infarction 80% of the patients it	Not applicable Patients questionnaire on participation in discharge planning.	The mean values were calculated for each of the three subscales, P-Information, P-Medical Treatment, P-Goals and Needs. Univariate analysis of variance (ANOVA)	29% of patients perceived that they had the opportunity to discuss the goals of their treatment with their doctor. 50% perceived that they had participated in discussions relating to their need for care/services after discharge. 1/3rd had perceived that they had participated in discussions of their

[1] Complete references for the quantitative articles included in the review, have been listed in the reference list within main thesis.

		e planning .	language were excluded	was the first stroke. Mean length of stay at hospital was 20.6 days.		was used to examine differences in demographic and clinical characteristics such as gender, education, living arrangement experience of stroke and P-ADL-performance in the three subscales of P-QPD. Multiple regression analysis was performed	need for rehabilitation after discharge. About 15% of the patients had the opportunity to discuss the goals of care/services and their rehabilitation after discharge. On the subscale P-Goals and Needs, the patients with a stay longer than 30 days had higher mean scores than the patients with a stay shorter than 11 days. Dependent patients had higher mean scores in P-goals and needs. Lower degrees of P-ADL performance at five days, higher

						to determine associated independent variables to perceived participation measured by P-QPD	degrees of P-ADL performance at 2–3 weeks after discharge, higher than an elementary school education and longer hospital stay were associated with a higher score in goals and needs. Length of stay was not significantly associated with P-Goals and Needs.
(Bertilsson *et al.*, 2014) Rehabilitation units (inpatient and out-patient home based units) Sweden	The aim of the study was to evaluate the effects of the client-centred ADL intervention with usual ADL training in patients' independenc	Multicentre Single blinded RCT	Cared for in a stroke unit less than 3 months after stroke onset, dependent in at least two ADL domains according	Intervention group/Control group N= 129/151 mean age was 74/71 years, 57% / 63% men 61% /	In CADL the first step is to establish a relationship in order to understand a person's lived experiences, patient identifies 3 goals for activities using COPM, OT observed the	Descriptive statistics of patient characteristics, univariate analyses of variance and multinomial/binomial logistic regression	There were no significant differences in any of the outcome measures. There was an increased focus of contact for goal-setting planning and evaluation in the CADL group 2.7 compared to 1.3 in UADL group.

	e in ADL, perceived participation, life satisfaction, use of home help service and satisfaction with training and caregiver burden, life satisfaction, and provision of informal care.		to Katz Extended ADL Index, not diagnosed with dementia and able to understand and follow instructions.	68% independent in Personal ADL and Instrumental ADL Mean of 25/28 days post stroke Median score of 65/80 in BI 31.8/41.7 in Stroke impact scale	patient performing the activity, patient learnt a goal–plan–do–check strategy to identify problems to do the activity, then OT and patient identified strategies to successfully perform the activity and in the last session they evaluated the strategies to be able to transfer the skill to situations outside therapy. UADL - The intervention varied in extent and methodology depending on the routines and practices of the	analyses were done as appropriate.	There was a significant difference between the CADL and the UADL groups in the SIS domain "emotion", in favour of the CADL Group. (P=0.04)

					OTs at the participating centres. Barthel index, Personal and instrumental ADL, Stroke impact scale, occupational gaps questionnaire, gait, satisfaction with life and training, home help service and care-giver burden.		
(Boonstra, Wijbrandi and Spikman, 2005) Inpatient rehabilitation centre	The study aimed to assess the feasibility of domiciliary therapy for patients with acquired brain injury	A feasibility study using the cohort design.	Patients with moderate to severe neuropsychological deficits, who were able to	16/22 had stroke, median values of : age 58 years, length of stay 151 days,	Intervention included home visits to assess situation and set goals in the first two instances. These were done by OT and cognitive	Descriptive and non-parametric tests were done on the data since the data was not normally	Before the start of therapy most goals set by patient and therapists were related to domestic activities. OT had set outdoor mobility goals while patients had

Netherlands	while they were still inpatients and to examine the goal-setting process for this domiciliary therapy.		transfer into a car, who did not have progressive neurological conditions of the brain and older than 18 years were included.	Time from onset 30days and 8 were men.	therapist. Therapy for goals in the following home visits was done by various therapists depending on patient's goals. There was no control group. Barthel Index, Hoensbroeck Disability Scale (HDS), and the first part of the Arnad'ottir OT-ADL Neurobehavioral Evaluation. Before the domiciliary therapy, patients were asked what main goal they wanted to attain. After the	distributed.	not. Patients had set self-care and leisure goals which the therapists had not set. Main goals set by the therapist were attained for the greater part or completely as reported by patients (17/20) and therapists (46/108 goals).

					domiciliary therapy, patients and their partners were asked whether the main goal had been attained. The OT who administered the observational home visits and therapists involved in the domiciliary therapy were asked to record the main goal set for the domiciliary therapy.		
(Combs *et al.*, 2010) Community and rehabilitation centres USA	To determine the feasibility and evaluate changes in activity and participation outcomes in	Case series design Pre, post and retention measures after 5	Patients who were 6 months post-stroke, had limited walking	N=9 with three women, age range of 45-78 years and time post stroke	Prior to therapy patients selected 5 tasks those were important to them and rated the quality of performance and satisfaction using	Means, SDs and effect sizes were calculated.	Overall mean scores of activity based and participation outcome measures improved at post intervention and retention. Large

	patients with stroke after client-centred intensive and task specific rehabilitation program.	months were done.	within community or unlimited walking within house, 45 degrees of movement in the shoulder, pick up and release washcloth, able to follow two step instructions and physician release to participate. Patients with orthopaedic	ranged from 2-20 years.	COPM.A bank of 50 skills based activities designed to address goals identified by patients was used during the training phase. These tasks were modified following intervention based on how meaningful the patient found it and based on researcher's input. Each participant was involved in 3hr 15 min program 5 days a week for 2 weeks with individualised task specific program (warm up, skill training,		effect sizes were seen for participation based measure SIS and COPM Post intervention (0.77-2.62) and moderate to large effect size in retention test (0.58-2.46)

			problems, prior stroke and cardio-vascular conditions were excluded.		ambulation and strengthening) and 30 min of home activities every day. COPM, Balance (Berg balance scale), timed up and go, mobility (6 min walk test), endurance, Wolfson motor function test and Stroke Impact Scale.		
(Demetrios *et al.*, 2014) Community based tertiary rehabilitation centre Australia	To examine the benefits of high intensity therapy compared to usual care following Botox A injections for post-stroke spasticity. Benefits	Non-randomised clinical trial.	Stroke diagnosis ≥ 3months, age ≥ 18 years, spasticity in UL or LL MAS ≥2, no contraindication to botox	HI group had 19/27 male, mean age of 60.6 yrs, time since stroke 2.3 years, baseline mean GAS score of	Patients residing within 12km of the research site were referred to the HI group and those residing outside were referred to Usual care. Individualised SMART goals were negotiated between therapist	Students T test, Wilcoxon rank test were used for differences. Multivariate logistic regression to determine relationship	93 goals were set collaboratively in HI group and 96 in usual care group. Goals were related to participation 21/12 for UL and activity and participation 34/44 for LL in HI/UC groups respectively. 75% vs 77.4%

	were evaluated by assessing goal achievement of patient-chosen goals.		injections, were eligible for rehabilitation and referred for botox injections.	31.3. Usual care group had 23/31 males, mean age of 61.4, time since onset of 2.5 years, mean GAS score of 36.4.	patient and carer (3-6 goals if both limbs involved) using GAS. These treatment goals were passed on to the treating centre. N= 28, HI group had ≥3 (1hr) sessions per week. Usual group n=31, had ≤2 (1hr) sessions per week. Therapy was individualised neurorehab program targeting goals based on neurodevelopemental approach. GAS at 6 weeks, 12 weeks and 24 weeks was	with variables	achieved more than 50% of their goals in HI/UC groups at 12 weeks. 78% vs 61% at 12 weeks and 78% vs 61% at 24 weeks in HI vs UC groups. There were significant differences in goal achievement within groups at all time points but not between groups. There was strong trend towards UL injected participants in HI group to achieve more goals at 24 weeks.

					measured. MAS, arm activity scale, 10 mt walk test, Subjective improvement and self-rated burden.		
(Deutsch, Maidan and Dickstein, 2012) Community USA	To describe implementation of motor imagery therapy for patient-centered goals in person and through tele-rehabilitation.	Single case study design.	Not applicable	38 year old female with stroke 10 years before, independent in assisted living complex, fearful and anxious in community ambulation and used cane for new	Patient goals for community ambulation were defined as walk quickly in hallway, walk in parking lot, walk in street leading out of building and walk in the mall. Imagery scenarios and scripts were constructed to address the patient's goals. 45-60 min sessions, 3/week for 4 weeks. 7 were in person	Descriptive statistics were calculated for outcomes.	57% increase in self- selected gait speed and 37% in fast speed and walking distance in 6min increased from 257 to 277 and 282mts. TUG reduced and balance scores increased from 65-76points.

				places and long walks.	and 5 were done by therapist remotely. Each session had physical and mental practice. Outcomes were chosen based on the patient's goals for motor behaviour such as Fugl-Meyer test, 10 min and 6 min walk test, timed up and go and Activities specific balance confidence scale.		
(Elsworth *et al.*, 1999) Acute in-patient rehabilitation centre, UK	To identify areas of weakness, or "training need" in the new rehabilitation goal-setting system at Rivermead	Mixed methods Audit using document analysis, observation, intervie	No criteria indicated 9 focus groups with all professionals with groups having 2-	The goal-setting process is audited in this study.	On admission within two weeks structured interview and questionnaire will be done to identify patient goals. In the initial goal-planning meeting	Pre-set criteria were checked in documents. Meetings were observed for occurrences	Aims in terms of handicap=66% Questionnaire administered=51% Rehabilitation aims relate to questionnaire=73% Aims that cater to emotional problem= 28%.

	centre where stroke patients were rehabilitated with other neurological cases.	ws and training need analysis using FG.	8 people in each. 2 new staff had semi-structured interviews on the same topics as for FG.		setting of goals at the level of disability, targets and aims are done. Goal review meeting conducted as needed before which interview and questionnaire are repeated.	based on guidelines. Priorities suggested for training were listed and counted.	
(Glazier *et al.*, 2004) Geriatric inpatient rehabilitation unit Canada	To evaluate the feasibility of use of a goal-menu in incorporating patient, family and team perspectives.	Prospective comparative study. Interviews using the goal menu were conducted. Open ended questions were posed to elicit	No criteria set	19 patients, 19 family members and 7 team members. Mean age was 80 yrs, 58% were women, average length of stay was 1.9 months,	Goal menu given to patients included functional, medical, psychosocial and future planning goals. There was no control group. Professionals set goals without the menu in a MDT meeting. Number of goals,	Frequencies were generated for each goal, agreement and disagreement between members were noted and percentage of agreement and agreement	Overall the family had the most goals 17.7 and focused on lifestyle, walking, coping, socialisation and levels of care. Patients focused on lifestyle, walking, spiritual needs and returning home. Staff focussed on giving information and walking. Agreement ranged between 28-72% between the groups

		additional goals not on the menu.		exact stroke numbers not known.	agreement on goals.	beyond expected (kappa statistic was calculated)	on the goals. Kappa statistic was poor <4 for all comparisons. Lowest concordance was found between family and team on future planning. Patients voiced dental and memory goals that were not on the menu. Mean time taken was 15mins to complete the goal menu.
(Gustafsson *et al.*, 2014) Inpatient rehabilitation unit with one day home therapy Australia	To describe the experience of an innovative program named Stroke rehabilitation enhancing and guiding	Mixed methodology design. Questionnaires were completed by professionals who	Members of STRENGTH team.	3 OTs, 4 PTs, 2 speech pathologists with five participants having < 1 year of experienc	One day in a week the inpatients who participated in the study were taken home and therapy was given for a goal-related activity by more than one member of the	Descriptive statistics were presented.	Therapists agreed that program assisted each of them to set goals with individuals and strongly agreed that it helped team set goals with individuals.

	transition home (STRENGTH) in the perspectives of the health care team.	worked on this program.		e in stroke care, while the other four had 3-14 years of experience.	MDT. Questionnaire regarding the program.		
(Holliday, Antoun and Playford, 2005) Rehabilitation services UK	To describe the goal-setting methods used in rehabilitation services in the inpatient and community focussing on the extent of patient involvement.	A postal survey to members of British Rehabilitation Medicine Members of the BSRM.	None	Seventy percent of respondents provided neurological rehabilitation services for people with stroke, multiple sclerosis, mild head injury, degenerative neurologi	NA NA	Descriptive counts of responses were done.	Most respondents did not routinely provide any verbal or written information about goal-setting before admission. Most goal-planning occurs during treatment sessions. A little over half of the respondents provided information about goals to patients. 30% usually do not routinely involve patients in the evaluative process.

				cal diseases. Ninety-one percent of respondents were doctors with 5 or more years of rehabilitation experience; 4% were occupational therapists, 2% physiotherapists, 2% nurses, and 1% speech and language			

				therapists.			
(Holliday *et al.*, 2007b) Inpatient Neuro-Rehabilitation services UK	To examine the impact of an increased participation goal setting protocol in a neuro-rehabilitation setting.	Optimised balance block design controlled study of goal-setting. Blocks repeated at 3 months.	Exclusion described as lack of functional communication whether due to having English as a second language, severe cognitive impairment or severe dysphasia.	Not specified	The critical differences between the two approaches were the use of a ‘‘goal setting work book’’ completed by the patient and the presence of the patient in the goal setting meetings. Patients were encouraged to work through the booklet with support from family and with their keyworker. The work book asked patients to prioritise activity, participation domains, identify specific tasks	Scores were examined to compare the two phases A with usual practice and phase B with increased participation. Mean scores were compared using Student t tests.	Overall goal relevance and proportion of goals found to be relevant were significantly higher in phase B. Satisfaction with the rehabilitation process was significantly higher in patients in this phase. There were no significant differences in proportion of goals achieved or other outcomes between groups.

					within those domains and what individuals wanted to achieve within the rehabilitation period. The goal setting meeting was an opportunity for therapists to discuss with patients both the projected outcome and the reasons for this. Patients had a long term goal with the predicted date for discharge and short term goals, that were ‘‘stepping stones’’ to the long term goal.		

					Patients' perceptions of involvement in goal-setting process were measured on a four point patient autonomy scale - Relevance of their goals -Duration of stay in days – Functional Independence Measure (FIM).16 – London Handicap Scale.17 – General Health Questionnaire (GHQ-28).18		
(Maitra and Erway, 2006) Inpatient, long-term	To comparatively analyse the perceptions of clients and OTs	Cross-sectional survey. Forty semi-structure	Currently receiving OT for 1 day or more, must be	Thirty patients with hip fracture, stroke, head	None	Descriptive statistics and one way ANOVA to was used to	72% of OTs encouraged their clients to participate in setting their goals. Only a fraction of

care or rehabilitation facility or nursing home. USA	regarding their involvement in the process of client-centered practice.	d interview questions developed from literature. It had both closed and open ended questions.	18 years of age or older, cognitively intact able to engage in a 10 min to 15 min interview.	injury or falls. Eleven OTs (8 females and 3 males) practiced in either a hospital (45% inpatient, 9% outpatient, 18% inpatient and outpatient), long-term care (18%), or nursing home (9%). Experience ranged from 4-20yrs.		compare the influence of facilities on client centred practice. Comments were presented along with the quantitative data.	clients said they assisted in setting goals. But 76% indicated more than half of their OT goals. 26% who did not want to participate said they had too much happening, wanted therapists to tell them, clinicians were the experts and none of them had heard about client-centred practice. Clients from nursing homes and out patients had better knowledge of their OT goals ($p=0.003$ & $p=.002$) compared to rehabilitation facilities; OPD patients assisted

							better in setting goals (p=0.012).
(McEwen *et al.*, 2009) Community stroke patients Canada	Effectiveness of CO-OP to an individual more than 1 year post-stroke, in achieving improved performance in self-selected functional goals, self-rated performance and satisfaction, stroke-related health status (including participation), self-efficacy and confidence?	Single case experiments with quasi-experimental pre and post design.	Participants who were considered to be motivated to participate and have an MMSE score >24 were recruited.	Three participants were working-aged men and all were right-hand dominant. As the participants were recruited from an out-patient education programme, original information about the type, location and severity	10 sessions of Cognitive program 1-2 per week, with first one or two to establish three personal goals and set baseline using the COPM. Treatment goals for each session are negotiated between patient and therapist. In subsequent sessions CO-OP intervention involving the global cognitive strategy (Gola-Plan-Do-Check) is taught, domain specific strategies are identified to solve problems	Mean and SDs using semi-statistical methods was done for the PQRS	For P1 significant improvements were seen during intervention and post-test for biking and swimming and for all goals at 1-month follow-up. For P2 Significant improvements were seen, as noted by two successive data points above the 2 SD band; these were seen during intervention for two of the three goals, for computer mouse at post-test and for all three at 1-month follow-up. P3 Significant

				of stroke was not available.	with performance and acquire the three goals. Therapist uses guided discovery to help clients find solutions, ongoing plans for skill acquisition and goal achievements are made jointly. Performance quality rating scale for each goal. Three trials of the functional activity were recorded at baseline, post intervention and at 1 month follow up. COPM, SIS, Stanford self -		improvements were seen during intervention for walking and yoga, at post-test for walking and for walking and nail clipping at 1 month follow-up.

					efficacy scale were done.		
(McEwen *et al.*, 2010) Community stroke patients Canada	To evaluate effectiveness of CO-OP in improving performance in three trained self-selected skills and one untrained self-selected skill.	Single case experiments with quasi-experimental pre and post design.	Participants who were considered to be motivated to participate and have an MMSE score >24 were recruited.	Three patients with stroke living in the community, two of whom were females, aged between 37-54 and, 12-35 months post stroke.	Four individual goals were established using COPM with patients in the initial session. Training using CO-OP principles is given for three of the four goals identified. COPM, SIS, Performance quality rating scale for each goal.	Descriptive statistics and two standard deviation (SD) band method to compare skill performance (PQRS) scores during baseline to intervention, post-test, and follow-up phases were done.	PQRS scores showed that all the skills showed 2 data points above 2 SD control limit for trained and untrained skills. COPM scores showed clinically significant improvement in satisfaction and performance for all goals except one.
(McGrath and Adams, 1999) UK	To explore the nature and prevalence of emotional distress in	Structured interviews were developed which explored		Forty stroke patients out of 82 participants.	Goal-setting using Life goals questionnaire where goals for rehabilitation are set based on goals meaningful	Descriptive statistics for HADS and Analysis of variance was done.	Frustration, sadness, fear, confusion, and worry were reported in the second week of admission in 23

	patients with acquired brain injury who were undergoing rehabilitation in an inpatient rehabilitation centre.	nine emotions or behaviours i.e apathy, behavioural inappropriateness, confusion, emotionalismfear, frustration, irritability, sadness and worry			to patients collaboratively. Hospital anxiety and depression scale.	Frequency counts were done for persistent fear.	patients. Thirteen patients spontaneously said goal-planning helped them cope. After week two, 19 patients remained in the study setting and only 4 showed persistent fear. Hospital Anxiety and Depression scores dropped to a level below clinical significance at the second assessment (after their first goal-planning meeting) and continued to drop at follow-up. A significant fall in anxiety score was demonstrated over the admission period, and this was maintained at follow-up (p =

							0.002).
(Monaghan *et al.*, 2005) UK	To determine how three forms of MDT care in stroke rehabilitation meet the standards set by the UK NSF framework.	Serial comparison pre and post-test design.		Twenty five patients for each of the three phases n=75.	Phase 1: Standard weekly meeting of members away from the ward with standard documents to include patient goals and carer involvement. Phase 2: A new form for the MDT meeting to enhance documentation of patient needs, goals and involvement with rehabilitation. All potential problems were listed so relevant problems can be circled along with prompts for setting goals and monitoring them.	Non-parametric statistics using Kruskal-Wallis and Mann-Whitney U test (pairwise analysis). Paired differences using Wilcoxon signed rank test.	Significantly more needs were considered in phase 2 ($p<0.001$) and phase 3 ($p=0.007$) compared to phase 1. Patient involvement was 0% in phase 1, 16% in phase 2 and 48% ($p<0.001$) in phase 3. Very few carers were involved in any of the three phases with a non-significant trend ($p=0.2$)

					Phase 3: A weekly MDT ward round by the bedside where treatment plans and therapy goals were discussed and where patients' relatives and carers were invited to attend, along with doctor involvement and use of the document used in phase 2. Day 7 post-stroke disability – Barthel Index Premorbid ability –Modified Rankin score Team climate inventory Average amount of time spent on MDT meetings		

					and ward round. Number of needs was documented, SMART goals, involvement of patients and carers were documented.		
(Nott, Barden and Baguley, 2014) Community-outpatient clinics Australia	To evaluate the achievement of goals chosen by patients following botox injections and explore association between client goals and clinical indicators of spasticity.	Pre and post-test design.	Adult patients with first onset of acquired brain injury with upper motor neuron signs of spasticity for more than three months.	28 adults, 15 males, of whom 22 had stroke, with average onset of 6.4 years with spasticity of Upper Limb and Upper Limb function of ARAT score 14.	OTs negotiated goals with patients and graded them based on GAS. These goals were discussed with the injecting doctor. Goal attainment scale (GAS) Tardieu scale Modified Ashworth scale for spasticity Action research arm test (ARAT)	Association between UL goals and receiving Botox injection to associated muscles was tested using chi-square analysis. Change in GAS scores at 4 weeks following botox injections using	Fifty goals were set by the individuals with the guidance of the OT. 90% of the participants identified goals involving distal UL muscles and all of them received injections in the distal UL muscles. GAS scores increased by 10 points from pre-injection to post injection with significant improvements ($z=4.02$; $p<0.001$)

						Wilcoxon test.	with an associated large ES (0.76).
(Rotenberg-Shpigelman *et al.*, 2012) Community rehabilitation day centre Israel	To examine the effectiveness of neuro-functional treatment (NFT) for attaining individualised goals in stroke survivors.	Block randomised controlled crossover design.	At least 1 year post stroke, adequate language skills to understand and participate in interview.	N=23 (16 women), with median age of 65 years, and mean time post stroke of 6.7 years and had moderate disability based on Rankin Scale. Group A= 12 Group B=11	Staff were trained for 10 hours in NFT principles. After a collaborative goal-setting with the patient staff defined the personal and environmental barriers to achieving goals and treatment plans were prepared to achieve goals. NFT was administered by staff members who acted as case managers. Between 1 and 3 goals were taken from patients' chosen goals and	Non-parametric statistical tests were carried out and effect sizes were calculated.	Median of 4.5 goals in group A and 5 in group B with no significant differences. Median treatment sessions was 9 (Range 2-20). Significant differences were found between groups in COPM with large size effects at the measurement point T2. Within group comparison of COPM also showed significant improvement in scores in targeted goals in both groups with large effect sizes.

					therapy was delivered for these for 3 months for group A and followed by for group B. NFT components included task specific training sessions, environmental and task adaptation, assistive devices, motivational recruitment and advocacy. COPM was administered for patients to determine goals by the case managers who also established a therapeutic relationship to get an		GAS scores showed 78% achieved at least one of their targeted goal but only 26% attained all their treatment goals. The SIS scale improved slightly in in both groups but not significantly after treatment in either of the groups.

					understanding of the patient's circumstances. GAS was used for staff to grade three of the five goals identified by patients. SIS was used for assessing quality of life. Measures were taken before and after treatment of both group A and group B.		
(Timmermans *et al.*, 2009) Sub-acute and chronic Netherlands	To assess skill training preferences for rehabilitation of arm and the motives for these preferences.	Cross sectional survey with semi-structured interviews using Motor activity	First stroke, aged over 18 years, clinical diagnosis of central paresis of arm and hand, within 3-	20 patients with sub-acute stroke and 20 patients with chronic stroke (24 males),	None Motor activity log was used to calculate use and quality of use of arm for preferred skills.	Statistical analysis to identify differences in patient characteristics was done. Use of skills and total	Holding an object while walking (52 total preference scores) and eating with knife and fork (61) were rated the highest in both groups. In sub-acute group bringing cup to mouth, using

		Log.	26 weeks or >12 months, MMSE score of >26, ability to read and write Dutch. Exclusion was due to having neglect, severe spasticity, orthopaedic impairments, Aphasia and apraxia.	age of 61 years, and mean MMSE of 28.2.		preference scores were analysed using spearman correlation co-efficient.	telephone and car steering wheel and in the chronic group writing, washing and drying body and sewing were skills included by patients. A positive Spearman Correlation Coefficient between skill preference totals and use totals was found ($r=0.64$, $p< 0.001$).
(Wressle *et al.*, 2002) Inpatient rehabilitat	To evaluate whether the use of a client-centred	Experimental design with experime	Inclusion was need for rehabilitation,	88 (34 had stroke) patients in experime	COPM was administered to the experimental group patients at admission and	Non-parametric tests using Mann-Whitney U	Median number of days was 24 in experiment and 26 in control group. The proportion of

ion, stroke rehabilitation and home rehabilitation program. Sweden	instrument, COPM affects the patients' perception of active participation in the rehabilitation.	ntal and control group was used.	ability to communicate, living not more than 30 mins by drive from hospital.	ntal 30 (11 had stroke) in control.	discharge. COPM was used only with the experimental group. Structured interviews were held 2-4 weeks after discharge. Klein-Bell ADL scale and clinical outcome variables (COVs) to identify functional goals.	test was used to compare assessments. Chi-squared test was used to compare results from structured interviews.	patients with stroke was comparable between the groups. Significantly more patients in the experiment group indicated that goals were formulated for their treatment, had a better ability to recall the goals and felt that they were active participants in the goal-setting process. Over 50% of the patients indicated that they had participated in creating their treatment goals, in terms of agreeing to a certain treatment, and working together with the staff.

Appendix 2.5. Data extraction table for qualitative studies included in the review [2].

Author, year and Setting	Aims and Objectives	Study design and methods	Inclusion exclusion criteria	Participant characteristics	Intervention (if any) Analysis	Findings
(Alaszewski, Alaszewski and Potter, 2004) UK One-year post stroke	To explore whether the bereavement model influences current professional practice and provides insight and understanding of stroke survivors' situation.	Three Focus groups and 34 interviews using topic guide. Four self-report diaries.	People who had a stroke one year after stroke, their family or friend and professionals who provided care for them.	Patients n=31 Age 38-89 years Mild to moderately severe stroke Professionals n=17	No intervention All transcripts were coded by the first author. ATLAS.ti. was used for data management. A sample of transcripts were coded by two other researchers. Then the themes were reviewed, grouped into areas or families.	Survivors and professionals saw life after stroke as period of change and adjustment and movement towards goals. The personal goals of survivors contextualised them within their personal biographies especially in terms of their identity and activities prior to stroke and how goals can contribute to the establishment of new identity, whereas professionals emphasised generic and functional goals. Survivors' goals were means towards more complex valued goals. Some professionals expressed goals to

[2] Complete references for the qualitative articles included in the review, have been listed in the reference list within main thesis.

						maximise function and gain independence which seemed more professional and distanced from patients' wishes while four of them encouraged a person-centred approach to set up goals. They emphasised broad adaptations to life and achievement of goals were a means to this end. In situations where there was disagreement over the nature of goals between patients and professionals, bereavement model was used by six professionals. They saw recovery as a process towards acceptance and if patients were stuck in any stage of acceptance, then they were unable to move on and progress with rehabilitation. When therapeutic relationship goes wrong professionals use the bereavement model to provide an explanation and indicate ways in which the situation can be addressed. For example

						patients when they have unrealistic expectations they are stuck in the stages of bereavement and need counselling to develop a more realistic set of goals. Breakdown in communication between carers was also sometimes attributed to being stuck in stages of bereavement and lack of acceptance of the situation. The goal-setting process seemed to work well when the therapist and client shared the same perception of goals. But when the goals were different between survivors and professionals they were classified as unrealistic. This caused problems in the relationship between professionals and patient. Patients in this study did not invoke the bereavement model but focussed on the present, set personal goals, were dynamic (not stuck), and sought help to develop their skills.
(Bendz,	To	Pheno	Patients	N=15, Men	No intervention	The aim of the stroke patient

2003) Stroke unit Sweden	understand how people who have had a stroke and their health care professionals understand the implications of a stroke and the rehabilitation process after it.	menographic study to understand how participants think and act. Open interviews at 3,6 and 12 months after stroke and document analysis	should be able to understand and express themselves verbally. Under the age of 65.	=9 and women=6. Ten had first stroke, were discharged home at three months, 13 were independent in self-care, and average length of stay was 5-86 days.	Each patient's interview data and document data was analysed as one unit and categories were defined. Then all data was analysed to describe similarities and differences between them. Categories and sub-categories were defined from whole data and compared to categories derived from individual units.	was to regain former social position or adapt to another position to avoid demands involved in their former social position. Patients believed that training to achieve their goals will help change their situation. For the professionals the aims of rehabilitation was to improve functions of the patients. No structured goals were expressed by patient or professional. No strategies were written to achieve patient goals.
(Boutin-Lester and	To explore and report	Phenomenol	Patients should have	3 women and 1 man	No intervention	All participants reported that process of goal-setting was

Gibson, 2002) Community USA	patients' perceptions of home health occupation al therapy.	ogical approa ch using unstru ctured intervi ews.	been discharged from home health OT and had minimum 5 visits by the same OT. They should be able to speak and participate in interviews.	with stroke included, Caucasians. N=5 (one had arthritis) Age 58-81 years. Duration of Home health OT 8 weeks to 6 months.	Preliminary codes were assigned, organised based on commonalities and differences in perceptions of participants by first author. Themes were developed by two authors. Field notes and member checking notes were used in collapsing categories into themes.	collaborative. They all expressed goals for therapy but some were general goals. If specific goals were expressed then they were accommodated by the OT. Contrary to goal-setting the treatment options were decided by the OT and were done by OT t the patient.
(Brown *et al.*, 2014) inpatient and early outpatient New Zealand	To explore patients' views of goal-setting during inpatient and early outpatient stroke rehabilitati on.	Semi-structu red intervi ews, 12 weeks after discha rge. Open-ended	Ability to engage in COPM, MMSE less than 24, aphasia, visual or auditory impairment , non-english speakers.	4 from the interventio n group and 6 from the control group. 7 men, age range 33-85, Range of FIM of 53-121 at admission,	The GS used COPM to elicit goals, information about these goals were disseminated to the team. Thematic analysis Coding followed by development of categories with higher level of	Rehabilitation according to participants was a situation that people responded to. They discussed the need to take things on a day by day basis to look ahead but not necessarily towards any specific goal other than to continually improve. Part of the problem to set goals by patients was the unpredictability of rate and extent of an person's recovery.

		questions were asked related to aims. As a part of RCT evaluating a structured method of goal-setting.		78-126 at 12 weeks, range of length of Stay 4-64 days and 16-30 weeks after stroke.	conceptualisation. Themes were documented and cross checked with other authors.	In this context short term goals are more important rather than long term goals. On the other hand goals were set to a highly ambitious level with the objective of exerting maximal effort and possible improvement. Some of these goals were done in secret and they found motivation in doing so even if they felt achievement of goal was unlikely. Goals often related to how things were before stroke. Their determination mainly and encouragement of others assisted patients to set goals. Struggling with mood and fatigue influenced the number of goals to be worked on. Short everyday goals helped lift the mood. Families provided support but were also a source of tension in deciding goals.
(Cott, 2004) Community Canada.	To understand the component	6 focus groups one of	Adults with adult-onset chronic disabling	Mean duration of disability 15 years,	No intervention Coded by two people. Author	Clients felt that they should be actively involved in defining their needs, important goals and outcomes, and setting priorities

	s of client-centred rehabilitation from the perspectives of adult clients with long term physical disabilities.	them with 7 stroke patients was conducted. Open ended and some specific questions regarding decision-making, goal-setting and service provision were	conditions, who had completed at least one course of rehabilitation in the publicly-funded system and who were able to participate in a 1 – 2 h focus group in English.	overall there were more females than males, and they had undergone rehabilitation in the past two years.	cross checked the codes, organised them under categories and developed themes. Ethno graph software was used.	in collaboration with health professionals. Participation in goal setting was positive if the client fitted into the mould that the programme provided. Usually these goals related to self-care, activities of daily living (ADL) and sometimes instrumental ADL. Participants reported more difficulties when their goals did not match those of the programme or the professionals. Particularly important to clients was retaining hope about their future, and not being 'written off'. All of the clients acknowledged their lack of preparedness to participate in decision-making, particularly in the early stages of their rehabilitation. This lack of preparedness related to being too ill or incapacitated, being uninformed about their condition, or being unable to accept the long-term implications of their condition,

		includ ed.				so that they were unable to participate appropriately in goal setting and decision-making.
(Daniels, Winding and Borell, 2002) Inpatient rehabilitatio n for stroke. Netherlands and Belgium	To identify the deliberation s of OTs in stroke rehabilitati on for their practice.	Two focus groups were condu cted. Data was analys ed based on Kvale' s approa ch.	Native Dutch speaking OTs with 3 years of experience in stroke inpatient rehabilitati on.	The Dutch group had 5/6 female OTs aged 26 to 34 having an average of 8 years of experience. The Belgian group had 3/7 female OTs aged 30 to 53 with an average of 19 years of experience in clinical rehabilitati on.	No intervention Researcher coded the natural meaning units in researcher's language. Researcher went back and for the examining the meaning units and original data to get a general knowledge of the data deriving three themes. Third stage was when the researcher interprets the findings within the theoretical context of occupational therapy.	Lack of awareness about impairments and abilities were thought to limit the extent to which patient could participate in decision making. The OTs restrained autonomy of patients in goal-setting due to their responsibility to protect patient from unsafe and unrealistic expectations. However they did not feel comfortable with this role. It was difficult to be client-centred in these situations. OTs mentioned institutional context was a limitation on the effectiveness of the service to set meaningful goals for patient. For example goals relevant to home could not be set as the patients were not aware of the problems and not ready to do compensatory training. OTs felt frustrated at this lack of connection to the home situation leading to goals that were not

						meaningful to patients.
(Elsworth *et al.*, 1999) Acute in-patient rehabilitation centre, UK	To identify areas of weakness, or "training need" in the new rehabilitation goal-setting system at Rivermead centre where stroke patients were rehabilitated with other neurological cases.	Audit using document analysis, observation, interviews and training need analysis using FG. Mixed methods 9 focus groups with all professionals with	No criteria indicated.	No details given	On admission within two weeks structured interview and questionnaire will be done to identify patient goals. In the initial goal-planning meeting setting of goals at the level of disability, targets and aims are done. Goal review meeting conducted as needed before which interview and questionnaire are repeated. No details of analysis given	Three occasions where professionals conflicted with what patients wanted to do. This was also reflected in group meetings. Some staff felt too much weight was given to patient opinion and were not comfortable with patient-centered working. Other training needs were theory and philosophy of patient-centred care, goal-setting, introductory pamphlets, guidelines, video training, skill training in communication, written and spoken and interpersonal skills.

		groups having 2-8 people in each. 2 new staff had semi-structured interviews on the same topics as for FG.				
(Guidetti and Tham, 2002) Geriatric or rehabilitation units Sweden	To describe what were the characteristics of the therapeutic strategies used by OTs during	Open ended Interviews Data was analysed using	OTs with a minimum of 5 years of experience delivering self-care training for stroke or	N=12; six OTs with stroke experience were recruited.	No intervention Transcripts were read, assigned meaning units in the language of the respondent, transformed into words of researcher	'Supporting the clients to set goals' The occupational therapists expressed how they created a 'seeing-situation' for the clients, which 'forced' clients to realize the significance of taking control over their own self-care activities. To be able to

	self-care training.	Empirical, Phenomenological and Psychological approach.	spinal injury patients were recruited.		summarised these under doing and thinking and moved on to general meaning and structure for all participants	see and set goals in collaboration with the occupational therapists, the clients needed to realize the value of having self-control. The occupational therapists emphasized the importance of the clients' roles as experts about themselves with the ability to 'give' their knowledge to others: 'Maybe I am the person who has supported them in this process – but it is absolutely not me who is the expert anymore.' The occupational therapists said that clients needed to understand the expectations and goals of the self-care training to prepare themselves for participating later in the training. The strategy used was to make explicit the expectations of the training, and the occupational therapists worked strategically

						together with the clients to carry out an 'exploratory run-through' with the aim of clarifying these expectations.
(Gustafsson *et al.*, 2014) Inpatient rehabilitation unit with one day home therapy Australia	To describe the experience of an innovative program named Stroke rehabilitation enhancing and guiding transition home (STRENGTH) in the perspectives of the health care team.	Mixed methodology design. Focus groups were conducted with professionals who worked on this program.	Members of STRENGTH team.	3 OTs, 4 PTs, 2 speech pathologists with five participants having < 1 year of experience in stroke care, while the other four had 3-14 years of experience.	One day in a week the inpatients who participated in the study were taken home and therapy was given for a goal-related activity by more than one member of the MDT. Open coding followed by preliminary themes which were tested by two researchers were inductively derived from data.	STRENGTH improved goal-setting practice. Team picked up things that patients needed to work on. Multiple visits gave rise to opportunity to work on multiple goals. The impact on goals was that they were more realistic from the perspective of patients and therapists. Clients were more involved in planning visits, testing in own environments encouraged realistic expectations and engagement in goal-setting process. Clients had new goals in home environment related to their realistic discharge situation. Therapists reported that their goals also became more realistic in terms of time frames and expectations.
(Hale and Piggot, 2005)	To explore the content of	Semi-structured	Purposeful sample of physiothera	20 PTs, 19 women, had	No intervention Open coding,	The PTs in the study encompassed a holistic approach because they subscribed to a

Community rehabilitation New Zealand	physiotherapeutic home interventions for stroke.	interviews analysed using grounded theory approach.	pists working across the nation who worked in structured HBSR programs.	community working experience of few months to over 10 years and worked in public or private health care system.	followed by refinement of codes, development of categories, developed into framework based on organisational scheme. The categories and subcategories were linked within this model.	patient-centred model of care. They attempted to address problems and requirements perceived by patients. A key intervention used was goal-setting based on what the patient wanted to do. One participant said PTs needed good listening skills, ability to guide patients and think laterally to work on what patient wanted to work on. All participants reported that success of interventions were primarily measured by attainment of goals participants set in conjunction with their patients.
(Hale, 2010) Community rehabilitation New Zealand	To explore the perceptions and experiences of community based physiotherapists new to	Semi-structured interviews (two face-face and two	Therapists with minimum one year experience working in home based stroke rehabilitation were	Four physiotherapists, female, with 6- 39 years of clinical experience working in community,	Training in the use of GAS with a 3-hr interactive workshop. Therapists were asked to discuss with the patient during the initial visit/s, the goals for physiotherapy and	One therapist found GAS patient specific and another found it helped to set patient-centred goals.

	GAS about its use with stroke patients.	over the phone), case notes from 7 patients, observations (2) and field notes were used for data collection. Interpretative descriptive analysis was done.	recruited.	and aged 29-60 years. All four had no prior knowledge of GAS.	set and scale two to three goals using GAS. The data from all sources were summarised as stories, sent to participants for cross checking and common themes were inductively extracted from these summaries.	
(Henshaw *et al.*, 2011)	To investigate	2 case studies	Mild to moderate	75 yr old woman 10	Functional goals were set with the	Both patients were able to identify goals, learn the Gola-

Inpatient rehabilitation USA	the use of Cognitive orientation to daily occupational performance (CO OP) –a task specific training program.	using mixed methods design using descriptive statistics. Semi-structured interviews, video-taped data and field notes relevant to this research are presented.	stroke, 6-18 months post stroke, more than 40 years old. Exclusion was mental illness, dementia, neglect, alcohol or drug abuse, aphasia and cognitive decline.	mo post-stroke with upper-limb ataxia, mild dysarthria, mild language difficulty, executive function problems, and decreased mobility. 65-yr-old woman 13 mo post-stroke with a right visual field cut and abnormal gaze, moderate cognitive impairment, self-	patient using COPM to identify three personally relevant goals. Participant behaviours, environmental contexts, and perspectives were analysed using content analysis approach. Themes were determined regarding the participant's experience and strategy use across treatment.	Plan-do, and develop domain-specific strategies with guidance, and both showed improvement in their chosen skills and some outcome measures. The impact of a motivating goal according one patient was willing to problem solve, more persistent in the face of challenges and less frustrated with performance due to increased motivation.

				reported executive symptoms, and intermittent numbness and tingling.		
(Hersh *et al.*, 2012a) Acute, inpatient and outpatient rehabilitation, community and domiciliary programs. Australia.	To explore how goal is conceptualised by speech pathologists in aphasia rehabilitation post stroke.	Semi-structured interviews followed by interpretative thematic analysis.	None stated.	The speech pathology participants (2males, 32 females) averaged 41 years old with a span between 24 years and 60 years. Five had been working for up to 5 years, 11 had been working between 5	No intervention Coding by individual researchers followed by developing categories and interpreted participant's perspectives of goals.	Goals as desires: SPs commented that that goals were what they wished for in response to an expressed desire from clients. Even when focussed on client's wishes SPs used words to improve specificity of goals at the concrete end of spectrum. So desire goals were made concrete by defining them as tangible, motivating, appropriate, suitable and collaboratively established. The key aspect in this theme is using clients' wishes as foundation for choices made about therapy. Impairment goals: Clinicians talked about impairment goals which

				and 15 years, and 18 had over 15 years of experience. They worked in six clinical areas (acute, inpatient rehabilitation, outpatient rehabilitation, private practice, domiciliary, and community groups), but with a quarter of participants working in inpatient and just over half in		contrasted with function goals because functional goals seemed to be more client-driven. So SPs suggested that functional goals must be relevant important and have real functional meaning for the person. Their comments suggested that client-centred goal setting was more viable when done in outpatients rather than in acute. Goals as contracts: There were suggestions that goals should be held as contracts to judge the efficiency of interventions; but this casting of goals in stone makes goals more professional centred than client centred.

				outpatient		
(Holliday, Ballinger and Playford, 2007a) Neuro-rehabilitation unit UK	To understand the patients' experiences of the goal-setting process with two different levels of involvement and identify factors influencing these perceptions.	Focus groups were conducted to collect data.	Exclusion described as lack of functional communication whether due to having English as a second language, severe cognitive impairment or severe dysphasia.	28 patients with mean age of 49 years with stroke, MS, haemorrhage, GBS and spinal injuries were recruited. 15 (nine men) patients were in the usual treatment group and 13 (seven men) were in increased participation group.	Usual goal-setting group had initial assessment before admission, main areas to be addressed agreed between patient and team, joint MDT assessment on day of admission, Goals discussed by therapists and patient in the first week, Goals set by therapists, copy of goals were given to the patient with opportunity to modify or disagree. In Increased participation group GS work book to define priorities, refine priorities, and define goals before admission. Key worker	Interaction with key worker was found to be important to understand the GS process. The quality of relationship with key worker helped patients to achieve objectives. If key worker was unavailable goal-discussions are limited. Getting to terms with condition was enabled by the collaborative GS process. Level of involvement in GS was influenced by information and beliefs about recovery. Increased involvement enabled them feel a sense of ownership, set tailor made goals individual and specific to them. Participants tended to reappraise life strategies following involvement in GS. Use of goals in the past at work made some patients feel they were being evaluated thus having a negative connotation.

					advocates for patient within goal-setting meeting and helps patient complete workbook. Goals set by patient and therapist together. Qualitative thematic analysis involving coding, categorising, and clustering these under themes.		
(Huby *et al.*, 2004) Elderly care wards UK	To investigate the organisational context of older patients' participation in discharge decision making.	In-depth case studies embedded in wider findings from data. Semi-structured	None described.	8/22 were patients with stroke aged above 60 years.	None	Data from observation and interviews were brought together in iterative analysis. No further steps described.	Authors suggest that some patients fail to engage in rehabilitation processes such as goal-setting which made staff to doubt patients' decision making competencies. Therapists spent time with patients deciding on their long term goals which were then broken down into short term goals achievable within a week. But lack of engagement was a source of frustration for staff, who ascribed this to lack of

		interviews and observation of team meetings. Informal chats with patients and professionals were done to understand case histories.					motivation. Researchers question whether the system fails to engage the patients due to routine systems, limited time and resource implications if patients were to be present in meetings. The researchers suggest that patients for whatever reason switched off and appeared passive in their relationship with the staff.
(Laver *et al.*, 2010) Acute stroke	To describe the readiness	Semi-structured	New diagnosis of stroke.	15 patients with stroke, age range	None	NVivo was used for	Participants had problems understanding what goals meant throughout all stages. 8 patients

unit Australia	and ability to set goals at different times for people with stroke.	interviews at three points acute, subacute and six months after stroke. Goal documents were analysed. EQ5D quality of life questionnaire was done following interviews.	Aged between 18-70 yrs, sufficient cognitive and communicative ability, EQVAS in acute ranged from 30-100, in rehab 25-100, in chronic 50-99.	36-70, 9 males, 9 lived with partner,		analysis. One person coded and categorised data. Themes were cross checked by two researchers. Goals were compared between documents and interviews.	in acute said they did not have goals. Most said that they wanted to get back to normal. In all phases goals were functional and oriented towards independence. Six months down patients wanted further recovery which included overcoming medical complications. Patients agreed with documented goals as relevant even though they did not recall specific goals. 12 patients retrospectively thought that clinicians had set goals with them but there was atleast one goal without participant's input. Seven participants in subacute said that they were not ready to set goals in acute stage. But six of the seven had set identified goals in the acute phase interviews. Six months down opinions varied about readiness to set goals- individualistic, some straightaway, some when some progress was made. Nine

							of them said they lacked knowledge about stroke and were unsure of what goals were realistic.
(Lawler *et al.*, 1999) Community rehabilitation UK	To examine the nature of the problems and concerns of the stroke patient and caregiver during the year following stroke and understand the nature of interventions done by specialist nurse.	Qualitative work involved semi-structured interviews with patients and carers and analysis of records of 120 patients kept by nurses	Patients who had been discharged from stroke units were recruited six weeks after stroke	30 patients and 15 carers were interviewed a year after stroke.	5 specialists nurses working in care of the elderly visited patients for 1 year to give advice, support and information focussing on social and emotio	Content analysis was done. Short summaries were done of records about situation, problems, actions and progress. Grounded theory approach was adopted for data analysis, categories developed sorted and	Nurses were aware of their influence in the goals setting process to motivate as well as demotivate the patients, of the patients' level of commitment to agreed goals, and limitations of interventions. So the strategy they adopt is not to try and agree goals but work with the patient through developing a relationship since they recognised the inappropriateness of imposed goals. Nurse responds vaguely to maintain motivation but not create unrealistic expectations or point the unrealistic nature of some hopes. Sometimes nurses felt it was better not to disturb the positive relationship. Sometimes they were directive in setting goals when they felt it was necessary for patient's recovery. They used their experience to

		and interviews with nurses. Purposive sampling to ensure subjects were representative of the larger study population in terms of severity and specialist nurse.			nal recovery.	labelled. Themes and patterns were derived.	decide which strategy to use.
(Leach *et al.*,	To describe	Semi-	Five	Eight	None	Framewor	Three models of goal-setting

2010) Sub-acute rehabilitation setting – Geriatric assessment and rehabilitation unit. Australia	the current practices of goal-setting (degree and quality of patient input) from the perspectives of the therapists.	structured interviews through emails. Used case samples of patients being treated in the facility to explore therapists' perceptions.	patients who had stroke and were treated by three disciplines were selected as case examples. The therapists who treated these patients were recruited.	therapists which included two speech pathologists, 3 OTs and 3 PTs.		k analysis was done to analyse data. Researchers familiarised themselves, derived preliminary themes for framework, key subject areas were established, and data was inputted in the framework, mapping and then interpretat	were seen: Therapist controlled (4), therapist led (10) and patient focussed (1). Patient focussed involved therapist introducing herself, her role, the process, Patient then used COPM to identify goals, goals identified will be negotiated by therapists with the goals identified by formal assessments. Therapist educated patient and family regarding the rehabilitation process and realistic goal-setting. The therapists perceived that patient-focused goal-setting increased patient motivation, maximises effectiveness of therapists time, allows for holistic management. A structured tool enables consideration of these holistic factors. The barriers were perceived as potential disagreement between patient and professional, inability of patient to contribute due to communication problems,

						ion was done.	tendency of patients to focus on external impairments, increased time, patients lack of knowledge about the rehabilitation continuum, stroke consequences, recovery, psychosocial consideration such as cultural differences, depression and feasibility of catering to patient goals.
(Levack *et al.*, 2009) Inpatient rehabilitation. New Zealand.	To investigate how clinicians talk about family involvement in goal-planning for rehabilitation	Semi-structured interviews.	Clinicians who had experience with goal setting, Based upon purposeful sampling: a wide range disciplines, experience, location of work (inpatient, outpatient and community	Nine clinicians from three centres, PT=1, OT=3, speech language therapists =2, registered nurses =2 (one of whom was a clinical nurse specialist)	None	As below	Family members were considered to be sources of information when patients were recovering from acute illness and set goals when patients had dysphasia or cognitive problems or when patients are overwhelmed with the consequences of the new disabilities. When family members set goals for the patient te clinicians used strategies to check if the patient agreed with the goals, reassured patients that when they recovered that goals can be altered by them or in some

			settings) and employment (public and private organizations).	Clinical psychologist = 1. Four of them had between 1–5 years of experience, four others had 6–10 years of experience, and one participant had more than 15 years of experience			instances family members were curtailed in contributing to goals. This happened when family members' agenda, goals and time frames differed from the clinicians'. They set goals to address their feelings of loss rather than patients' best interests. These members are considered as barriers to development of relationship with patients. Clinicians wanted to protect these patients from over expectation of family members. They sometimes avoided engagement with family. However not all families were rejected as clinicians did discuss education, support and information but goals were just set for the patient.
(Levack *et al.*, 2011) Inpatient rehabilitation. New	To investigate the application of goal setting in	Grounded theory approach. Data	Patients admitted for rehabilitation following	N= 44 Patients =9 Age range 57-92yrs, 4 males, Length of		Data coding was done line by line. Data was	Patient and family goals gathered using a structured questionnaire was recorded in the interdisciplinary plan sheet along with team goals. Professionals tended to prioritise

Zealand.	inpatient stroke rehabilitation.	collected using semi-structured interviews with patients, family members, and clinicians, observations of ward meetings, assessment sessions, other	stroke. Purposeful sampling to include men and women, people of different ages, different ethnicities, and different Severities of stroke.	stay 18-90 days. Family members= 7 Professionals=28 Doctors= 6 Nurses=11 PT=4, OT=3, Social workers=2, Speech therapist=1.		explored with higher levels of conceptualisation, memo writing and diagramming.	some goals that were called privileged goals when they were oriented to physical functioning, shorter time frames with conservative estimations of progress. This concept conflicted with other values like patient-centredness. Patients and families brought up goals which were unexpected (not privileged goals) clinicians tried to navigate conversations to familiar territory; they did this by ignoring statements or emphasising their professional goals.

		clinical activities and analysis of clinical documents.					
(Lloyd, Roberts and Freeman, 2014) Acute, sub-acute and community stroke rehabilitation centres. UK	To explore PTs perceptions about involving patients in goals-setting early after stroke.	Grounded theory using semi-structured interviews.	PTs with different levels of experience, job grades and working in different types of rehabilitation setups.	9 PTs working in stroke rehabilitation with access to early supported discharge services and units having a length of stay in two sites 10-21 and third site being >21 days.	None	Constant comparative method of grounded theory which involved open coding, focussed coding to group similar ideas linking them to collaborat	PTs in this study suggested that patients have to come to terms with their stroke in order to be able to contribute to goal-setting. Coming to terms depended on health factors such as type of stroke, severity, personal factors such as patient's age, thinking patterns, coping style, previous disabilities and illness experience and environmental factors and passing of time. They also suggested that with experience PTs move from a mechanistic view of goal-setting to greater focus on patient empowerment valuing

				Experience on average from 2.75 months (novices) to 11 years (very experienced). Age range of 20-50 years,		ive goal-setting. Categorisation at higher level of abstraction resulted in focused codes being integrated into theoretical categories.	communication skills. Learning occurred by working with experienced staff, but having a rapport with patients for collaborative goal-setting is also an innate skill. They suggested that they required sophisticated communication skills to negotiate and find a balance for patients within the restrictions of the hospital and available resources. They have to manage patient expectations within multiple expectations such as families, MDT, organisation and external agencies. They sometimes acted as mediators between patients and MDT (novice). But sometimes produced goals deemed acceptable due to pressure (experienced). The culture and busyness does not empower patients. Patients delegate responsibility to PTs which was acceptable (experienced). They left it with the patient to engage but also said they needed to

							assess their ability and desire to participate, empower patients and maintain hope.
(Northen *et al.*, 1995) Adult rehabilitation centres USA	To describe the extent to which OTs involved patients in goal-setting process.	Mixed methods Two episodes of OT evaluation of patients were observed and recorded. The patient's notes were analysed to see if patient partici	None specified.	30 OTs (4 men) from 10 different rehabilitation facilities in three states in USA, range of experience 1.2-24 years. Patient details are not included except that patients with CVA were included (exact numbers not	None	A-priori method of concept coding using PPEF. Patient participation and evaluation form (PPEF) was designed for this study and the PPEF criteria included items to orient patients to occupational therapy	Percentage sores of what items were attempted and corresponding numbers of applicable items for each evaluation were calculated. It ranged from 17.4% to 78.9 % with an average of 43.3%. The six highest scoring OTS were aged on average 35.7 years, 1.2 to 20 years of experience. All or majority of these 6 OTs collaborated with patients to establish goals, explained additional goals, stated goals in simple language and involved patient/family in the formulation of treatment plans to extent possible. Methods used to involve patients included documentation of participation, including patients in deciding goals and plans, explaining goals not identified by patient. OTs did not seem to elicit and respond to

		pation was recorded. Thirdly the participant was interviewed to collect information on knowledge, use of participation approaches and factors influencing this		known).		services and to the treatment and potential outcomes, elicit and respond to patients' concerns, and to collaborate with patients to establish treatment goals. The audio tapes were reviewed based on these criteria.	concerns, document rating of goals and explain to patients how to participate in goal-setting. Overall on average OTs used fewer than half of the 23 PPEF items to involve patients in Goal-setting.

		approach to participation.					
(Parry, 2004) Inpatient rehabilitation UK	To analyse patients' and therapists communication practices during physiotherapy goal-setting for stroke rehabilitation.	Of the 74 sessions recorded 8 goal setting sessions were observed in physiotherapy gyms in four stroke in-patient rehabilitation gyms.	None described.	21 stroke patients (11 females) with an age range of 52-86 years and no one had severe aphasia. Ten PTs were involved (9 females), with experience ranging from 3-23 years. The 8 goal-setting episodes involved 6 patients and and 4 PTs	None	Conversational analysis within Ethnomethodology perspective.	Goal-setting was not a frequent practice within treatment session. In 7 of these sessions the problem was introduced by the PT for which goal was set later. Patients' independent views of their problems were not sought. Usually patients agreed these proposed gaols sometimes after interactional work by the therapists. When attempting to elicit problems therapist pursues responses that restrain the sort of problem he introduces (therapist relevant problems for goals). Therapist establishes some form of shortcoming in his ability and then reformulates the goal based on this. In writing the goal it is transformed to fit with patient's portrayal of problem. There were interactional difficulties between therapists

		1 patient centred case described in detail.					and patients, id not agree to therapist's goals straightaway, guarding against exposure to inner self-competence by patients and professionals, time factor and social constraints where patients adopt a lower standing is observed.
(Playford *et al.*, 2000) UK	To explore views of goal-setting from different health care professionals.	A workshop to stimulate discussion about goal-setting and data was collected by transcribing the discussions	None specified	16 people from medicine, OT, Pt, nursing attended. Three were from inpatient stroke rehabilitation unit, one from community stroke rehabilitation unit, three from neuro-rehabilitati	None	The flip chart notes were transcribed and analysed. No further details of analysis.	A client-centred handicap based method of goal-setting in which short term objectives are specified and contribute to the life goals (aim) of the patients are set was used in the inpatient-rehabilitation setting. The life goals questionnaire was used to explore goals with patients. The community stroke team discussed patient needs but clearly distinguished team goals which are in the best interests of the patients and goals articulated by person. If patient goals are considered not achievable they are replaced by other goals depending on teams' ability. Context-sensitive goal-setting requires an intimate

		on flip charts. Discussions were about current practice, difficulties associated with setting goals, and lessons learned.		on unit and one from elderly care.			knowledge of patients which takes weeks and may never occur. The amount of time spent with patient rather than MDT assessments should determine goals. This was seen as role of key worker. Hoe visits were considered useful to identify patient's needs, roles and family conflicts. Patients were considered not be ready to set goals early during onset of condition since they might have anxiety and had no vision for themselves and their future. They may not express their goals due to modesty and shame and physical disability which takes precedence. Patients in the outpatient department seem to have more appropriate goals and higher satisfaction with the process. Goals that were negotiated with the patients were found to be more successful. Most goals however are owned by the team because professionals do not

							acknowledge goals that they are unable to handle, conflicts in speed of actual recovery and patient perception of recovery, patient not expressing their opinion but concurring with team.
(Rohde *et al.*, 2012) Inpatient and outpatient rehabilitation unit Australia	To explore whether there were differences between goals of patients with aphasia and their Speech and language therapists.	Semi-structured interviews of patients and speech and language pathologists.	For patients the criteria was their ability to participate in an interview, attending out-patient therapy and ability to give reliable yes or no responses.	Three SALT with minimum 3 years of experience of working with people with aphasia. Four patients with aphasia who had had rehabilitation ranging from 2-5 months receiving up to 5	None	Qualitative content analysis to identify, condense, meaning units, to create codes, categories and themes.	For patients goals were focussed on improving communication to return to valued activities, social contacts or hobbies. Gaining communication skill was a means to achieve these higher goals. SALT goals were focussed on impairments through discussions with clients or based on assessments. Goals related to functional activities were also included based on patients' choice. Most goals of patients and therapists matched or some were linked indirectly. Mismatch occurred when goals related to highly valued activities were voiced by patients. Reasons for this mismatch were suggested as

				sessions per week.			goals being outside of scope of SALT, physical, cognitive and communicative abilities and limited context of rehabilitation.
(Suddick and De Souza, 2006) Stroke, neuro rehabilitation units and community. UK	To explore perceptions of OTs and PTs towards their team and team working.	Semi structured interviews	PTs and OTs with less than a month of experience in their work setup were excluded.	Five OTs and 5 PTs with 1.5 to 13 years of experience and 8 of them were females.	None	Content analysis was done. Pamphlets were developed and member validated and amended.	The occupational therapist and physiotherapist based in Team C explained that patient goals were set and discussed within their weekly multidisciplinary team meeting using an multidisciplinary team goal-setting form, again without patient or family attendance. Although Team A and Team B reported more interdisciplinary teamwork practices than Team C, team members from both Team A and Team B reported that they did not necessarily include patients and their families more within the goal-setting process. Two respondents felt

							that patients' cognitive ability limited how much they could be included, others suggested that patients should be included but were not, or that patients were considered to be outside the team and would not know their rehabilitation needs as they lack the expertise.
(Timmermans *et al.*, 2009) Sub-acute and chronic Netherlands	To assess skill training preferences for rehabilitation of arm and the motives for these preferences.	A cross sectional survey using semi-structured interviews using the Motor activity Log. Mixed metho	First stroke, aged over 18 years, clinical diagnosis of central paresis of arm and hand, within 3-26 weeks or >12 months, MMSE score of >26, ability to read and write	20 patients with sub-acute stroke and 20 patients with chronic stroke (24 males), age of 61 years, and mean MMSE of 28.2.	None	Qualitative open coding of interview data to identify motives was done.	The motives were hope on transfer to other activities, avoid frustration, avoid embarrassment in public, independence, not to be a burden to others, pride, joy, back to work. It seemed that patients were mostly driven to improve their participation level, rather than their impairment and activity levels.

		d though author s do not mentio n it.	Dutch. Exclusion was due to having neglect, severe spasticity, orthopaedic impairment s, Aphasia and apraxia.				
(Wottrich *et al.*, 2004) Neurological and Geriatric rehabilitatio n units. Sweden	To explore, describe and compare characterist ic of physiothera py sessions in the view of PTs and patients.	Semi-structu red intervi ews and observ ations. PTs invited their patient s to partici pate. Topics	Aphasic patients	9 patients with stroke, mean age of 58 years, 3.5 months after stroke, and 6 males. Ten PTs with mean age of 40 years, mean 2.5 years of stroke experience, 7 males	None	Searching and identifyin g units of meaning consistent with the aim of the study, sorted into categories and themes were identified.	Both patients and PTs considered it important that they should agree on clear and achievable goals to decide what to do in each session. PTs were eager to praise the patients' efforts towards the set goals but this encouragement was seen as undeserved by some patients as they had not accomplished much.

		evolved from observations for interviews.		were included.			
(Wressle, Oberg and Henriksson, 1999) Inpatient and 2 weeks post discharge. Sweden	The aim was to describe the rehabilitation process of the geriatric stroke patient from perspectives of patient and professional.	Qualitative interviews with patients and professionals. Follow up interviews were planned after discharge but were done	Patients should have the ability to communicate and being at an early stage of the rehabilitation process. The staff members interviewed were the persons who treated the particular patients.	Five patients were interviewed with an average age of 82 years, four were women, and all had cerebral infarction. Five PTs, 5 OTs and 5 doctors were interviewed.	None	Grounded theory analysis of data with coding, categorisation and derivation of themes was done.	One of the PTs stressed the importance of the patient's participation in the goal-setting process. It was not obvious from the OT interviews that goal-setting was done together with the patients. They discussed methods and interventions rather than goals and also considered patient's motivation as a pre-requisite more than a goal. In some cases professionals considered outcomes of rehabilitation by achievement of goals, but in some cases if goals were not being achieved patients were being discharged home if possible.

		in three cases only. (N=30 interviews) Diaries recorded by professionals were analysed n=19					
(Young, Manmathan and Ward, 2008) Neurorehabilitation unit and community UK	To explore perceptions of rehabilitation goal-setting in the view of patients, carers and professionals.	Semi-structured Interviews were held with inpatients and patient	Informed consenting ability, attendance at two goal-setting meetings and have a non-progressive neurologica	10 participants in each group mean age of inpatients was 39.1, average FIM was 61, attended	Regular goal-setting meetings are conducted along with review meetin	Content analysis was carried out and themes were derived. Frequency counts of these	Staff and carers valued the interactive format, liked the feeling of working towards shared goals, increased confidence and provided reassurance. With this approach of goal-setting all patient's views on choices of goals were solicited. Despite this patients, staff and carers felt that their role in

		s who had been discharged within the past two years. Stroke numbers not given.	l disorder.	3.3 goal-setting meetings. The mean age for discharged patients was 43.4, average FIM was 76.1 and had attended 3.9 goal-setting meetings. Most common condition of patients was stroke and traumatic brain injury.	gs. The first meeting involved the patient carers and Multi-disciplinary team within a 2 week period. Goals for the next 4 weeks are agreed with the patient, and	themes were done across all transcripts.	determining goals was passive because they lacked expertise in rehabilitation or knowledge of prognosis. 9/10 staff felt account was taken of patient's views and lay carers and patients might lack confidence to express their viewpoint. They were concerned that patient might feel under pressure to accept goals and worried that certain topics might be difficult to discuss. However patients and carers approved of self-care goals and used specific examples of very personal goals in their interviews. Patients suggested that they would set goals for themselves personally. Potential suggestion to improve the process included goals needed to be explicit, comprehensible, and something the patient could aspire to, "you tailor your goals … to something meaningful for the person". The key worker who advocates

					at each subsequent meeting feedback is shared about progress towards previous goals, new or revised goals chosen, and the date is set for the next review		for the patient should get to know patient well and become familiar with records beforehand. Documentation during meeting n the presence of patients made them feel that their input was valued. Patients wanted a copy of the goals and feedback on how they met their goals.

Appendix 2.6. Quality assessment of the methodological aspects of the quantitative studies included in the review

Study	**1**	**2**		**3**		**4**				**5**			**6**		**7**			**8**			**9**			**10**				**11**		**12**		
		a	**b**	**a**	**b**	**a**	**b**	**c**	**d**	**a**	**b**	**c**	**a**	**b**	**a**	**b**	**c**	**a**	**b**	**c**	**a**	**b**	**c**	**a**	**b**	**c**	**d**	**a**	**b**	**a**	**b**	
(Wressle *et al.*, 2002)	√	√	√	√	x	√	E	x	-	√	√	-	x	x	√	√	x	√	√	-	√	√	√	I		√	-	√	√	√	√	
No difference in groups functionally or other characteristics at baseline. Patient perceived involvement was better and they recalled goals better in experimental group. No similar studies done. COPM if used properly can help patients to involve in goal-setting and ability to recall goals. But training and costs for use of COPM must be factored.																																
(Timmermans *et al.*, 2009)	√	√	x	√	x	√	S	x	-	√	√	-	-	√	√	√	√	x	x	x	-	-	-	G	√	-	√	√	√	√	v	
Study indicates that patients choose skills that they will normally use in daily life. Hence indicate patient chosen skills should be trained for. All these skills were functional goals.																																
(Rotenberg-Shpigelman *et al.*, 2012)	√	√	√	x	x	√	BRCT	√	√	√	x	√	x	x	√	√	√	√	√	-	√	√	x	I	I	√	x	√	√	√	√	
Intervention clearly described. Individual goals were selected and COPM was used to grade the performance and satisfaction with these goals. Activities were trained to cater to these goals by using NFT. Case manager also established therapeutic alliance which helped to understand the environment and personal barriers to achieve goals. COPM improves pre and post interventional satisfaction and performance in other studies.																																

Intensive training for goals may not be possible for all stroke patients. QoL did not improve in any of the groups. But perception of performance and satisfaction improved for all patients to a high level and GAS achieved in all goals for 26 %. Methodologically rigorous except small numbers and lack of blinding.																																	
(Nott, Barden and Baguley, 2014)	√	√	x	x	x	√	E	x	-	-	-	-	x	x	√	√	√	x	-	-	√	√	x	I		√	-	√	√	√	√	
Methodologically rigorous but a small scale study with no blinding. Most important of all how did the patient goals (the injecting doctors were told about the goals) influence the muscle injection decision is not totally clear. So it is only a logical link that since 90% received distal injections and their goals were distal their injections might have been given to goal oriented muscles; hence goal achievement due to BTX to these muscles (pertaining to patient chosen goals) is a link made from findings not originally aimed.																																	
(Northen *et al.*, 1995)	√	√	x	x	x	x	MM	x	-	x	x	-	x	√	x	x	x	x	x	-	-	-	x	I		√	-	x	X	x	x	
Used qualitative methods to collect and analyse data but used frequency counts to present findings. There was high variability in age range, experience, training amongst OTs and was not correlated to their PPEF scores. So influencing variables cannot be specified. Vague, methodologically flawed, just small samples suggesting potential effects based on practice. Needs further studies to validate.																																	
(Monaghan *et al.*, 2005)	√	√	x	√	x	√	E-SC	x	-	-	-	-	x	x	√	√	√	x	x	x	√	x	x	I		√	-	√	√	√	√	
No difference in all groups functionally. But more needs were noted and patient involvement was better and more goals were discussed with them in phase two and three. Methodologically moderate, within limits of a complex interventional study.																																	
(McGrath and Adams,	√	√	√	-	-	x	Q	x	-	-	-	-	x	x	x	√	√	√	x	x	√	x	-	I	I	√	-	√	√	x	x	

1999)																																
Vague, methodologically flawed, just small samples suggesting potential effects based on practice. Needs further studies to validate.																																
(McEwen *et al.*, 2009; McEwen *et al.*, 2010)	√	√	x	√	-	√	CS	x	-	√	x	-	x	x	√	√	√	x	-	-	√	√	√	I	I	√	-	√	√	√	√	
No difference in all three functionally. They achieved their aims to a high level post intervention and at 1 month follow up,																																
(Maitra and Erway, 2006)	√	x	x	x	x	√	S	x	-	-	-	-	x	x	x	√	-	x	-	-	√	-	x	I	I	√	-	-	√	x	x	
Vague, methodologically flawed, just small samples suggesting potential effects based on practice. Needs further studies to validate.																																
(Holliday *et al.*, 2007b)	√	x	x	√	√	√	BB D	x	-	√	√	-	x	√	√	√	√	x	x	x	-	x	x	I	I	√	-	√	√	√	√	
No difference in both groups functionally but perceived participation, satisfaction were better in increased intervention group. Methodologically moderate, result reporting weak due to brevity of journal.																																
(Holliday, Antoun and Playford, 2005)	√	x	√	√	x	√	S	-	-	-	-	-	-	-	√	x	-	√	-	-	-	-	-	I	I	√	-	√	√	√	x	.
Relevant to UK practice. But survey included majority physicians no other therapy professionals who us goal-setting regularly. Hence cannot extrapolate all rehabilitation professionals																																
(Gustafss	√	√	x	x	x	√	S	-	-	-	-	-	-	-	x	x	x	-	-	-	√	x	x	I	I	√	-	√	√	x	x	

on et al., 2014)																																	
Limited use as methodologically weak. Biased assessment tool. Program needs to be delivered more widely to evaluate outcomes. Outcomes should be objective.																																	
(Glazier *et al.*, 2004)	√	x	√	√	x	√	F	x	-	x	-	-	-	x	x	x	x	-	-	-	x	x	x		I	√	-	√	√	√	√	
Intervention clearly described. Can be adapted to local setting. Larger studies need to be done to validate tool. Stroke numbers not clear. Stroke specific studies needed. Patients had different goals compared to their family members, identified new goals such as dental and memory needs. Lowest concordance with family was about future planning and spiritual needs with the team.																																	
(Elsworth *et al.*, 1999)	√	√	√	-	x	√	A	x	-	-	-	-	x	x	x	x	-	√	-	x	√	x	x	-	-	√	-	√	√	√	√	
Intervention partially described. Process seems to have helped at the start of program but staff were not following all steps when compared to previous audit. There is scope for improvement in the process in this practice.																																	
(Deutsch, Maidan and Dickstein, 2012)	√	√	-	-	-	√	CSt	x	-	-	-	-	√	-	√	√	√	-	-	-	-	√	x	I	I	√	-	√	√	√	x	
MI delivered for PC goals was effective in this case study. However multiple case study design would be better to improve transferability.																																	
(Demetrios *et al.*, 2014)	√	√	√	√	√	√	QE	x	x	√	√	-	√	x	√	√	√	√	√	√	√	√	x	√	I	√	√	√	x	√	√	
No difference in both groups but both groups improved in goal-achievement. Hence patient-centred goals and goal-oriented therapy seems to have influenced outcomes more than intensity of therapy. Botox in UL in HI group had better goal achievement																																	

at 24 weeks.																																		
(Combs *et al.*, 2010)	√	x	x	-	x	√	CS	X	-	-	-	-	x	x	√	√	√	√	-	-	√	√	x	I	I	√	-	√	√	√	√		
Intervention clearly described. COPM was used to decide goals. Activities were trained to cater to these goals. COPM improves pre and post interventional satisfaction and performance in other studies. Intensive training for goals may not be possible for all stroke patients. This did not result in significant changes in activity based outcomes. But perception of performance and satisfaction improved for all patients to a high level.																																	
(Boonstra, Wijbrandi and Spikman, 2005)	√	√	x	-	-	√	CD	x	-	-	-	-	x	x	√	√	x	√	-	X	√	x	x		I	√	-	√	x	√	√		
Intervention clearly described. Not clear if cognitive therapists are available to help assess and set goals at the start in the UK context. Goal-setting seems to be more relevant to patient when done at home. Goal-setting during domiciliary therapy identified goals relevant to patient and better overlap between patient and professionals in goals. First study to involve cognitively impaired patients in setting goals.																																	
(Bertilsson *et al.*, 2014)	√	√	x	√	√	√	RCT	√	√	√	√	-	√	√	√	√	√	√	√	-		x	x	√	I	√	√	√	√	√	√		
Intervention clearly described. But requires specialist training. Other small scale studies using this strategy have found significant differences. Patients perceived better participation in the care of emotions in SIS scale which indicates that emotional health cab be better with an approach such as this. More time was spent discussing goals in the interventional group.																																	
Almborg (2008)	√	√	√	-	-	√	CrS	x	-	-	-	-	-	x	√	√	√	√	-	-	√	x	x	x	I	√	-	√	√	√	x		

Patients perceived decreased participation in discussions regarding goals and needs probably due to lack of routine procedures that include patients in goal-setting and identifying their needs.	
LEGEND: √- Indicates positive quality aspect x- Indicates negative quality aspect - -Not relevant E- Experimental	 S- Survey BRCT- Block Randomised controlled Trial E- Experimental MM- Mixed methods SC-Serial Comparison Q-Questionnaire CS- Case Series BBD- Block Balanced Design F- Feasibility A-Audit CSt- Case Study QE- Quasi Experimental CD- Cohort Design RCT- Randomised Controlled Trial CrS- Cross sectional

Template to Assessing Quality.

1. Did the study address a clear focus?
2. Selection Bias

a. Are the individuals selected to participate in the study likely to be representative of the target population?

b. What percentage of the selected individuals agreed to participate?

3. Sample size

a. Was the sample size appropriate?

b. Was sample size determination carried out?
4. Design and Method
a. Was the design and method appropriate?
b. Indicate the study design
c. Was the study described as randomised?
d. Was the method of randomisation described an appropriate?
5. Confounders
a. Were there important differences between groups prior to intervention?
b. What were the confounders?
c. Were they controlled for in the design or analysis? If so what percentage?
6. Blinding (Observer bias)
a. Was the assessor aware of the intervention or exposure status of the participants?
b. Were the study participants aware of the research question?
7. Data collection methods
a. Were the data collection tools shown to be valid?
b. Were the data collection tools shown to be reliable?
c. Were the assessments done for all outcomes?
8. Withdrawals and dropouts
a. Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?
b. Indicate the percentage of participants completing the study. If the percentage differs by groups, record the lowest.
c. Was the follow up complete enough and long enough? (Cohort study)
9. Intervention integrity (appropriate intervention/performance bias/Hawthorne effect/)

a. What percentage of participants received the allocated intervention or exposure of interest?
b. Was the consistency of intervention measured?
c. Is it likely that there was an unintended intervention that may influence the results?
10. Analyses
a. What was the unit of allocation?
b. What was the unit of analysis?
c. Are the statistical methods appropriate for the study design?
d. Was the analysis performed by intention to treat rather than the actual intervention received?
11. Reporting Bias (Selective reporting)
a. Is there a systematic difference between reported and unreported findings?
b. Clearly presented results (Precisiveness).
12. Can the results be applied to local context?
a. Do the results fit with other findings?
b. What are the implications of this study for practice?

Appendix 2.7 Quality assessment of the methodological aspects of the qualitative studies included in the review

Study	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**
(Young, Manmathan and Ward, 2008)	√	√	√	√	√	x	√	√	√	√	√	√	√	√	√
Naturalistic data collection but authors state this might have been uncomfortable for patients. Families represented some patients which may not be ideal. Staff might not have spoken their minds as they were small in number and might have had fear of being identified. Explains the methodology clearly. Context is UK practices. But there is a specialised GS method which is not prevalent in other parts of UK. Suggests helpful strategies to build patient centred goal-setting methods.															
(Wressle, Oberg and Henriksson, 1999)	√	√	√	√	√	x	√	√	√	x	x	X	x	√	√
Findings presented under themes with no data as evidence. Methodologically moderate study, not reliable since evidence is not presented. Data saturation is not discussed. No member checking reported. Shows GS was not done together with patients even if one PT said it was important. OTs did not mention collaborative goal-setting.															
(Wottrich *et al.*, 2004)	√	√	√	x	x	x	x	√	√	√	√	X	x	x	√
Patients were recruited by PTs treating them. Hence there is the pressure and responses could be biased. No audit trail provided. Interview questions were derived from observations. Not piloted. The context of study is clear and relevant to UK practice. Limited rigour strategies adopted except for analyst triangulation. Quotes from patients do not relate to interpretation in places. Methodological and reporting weaknesses present. Evidence inadequate for interpretation.															

Data does not relate to themes in some places. Descriptive data analysis where themes and subcategories are not linked.															
(Timmermans *et al.*, 2009)	√	√	√	x	x	x	x	X	x	x	√	X	x	x	x
Methodologically weak study, measures of rigour not clear. Qualitative data was a small component of the study and hence adequate data has not been presented. Implies that patients chose activities due to their motives for better participation.															
(Suddick and De Souza, 2006)	√	√	√	√	x	x	√	√	√	x	√	x	x	x	√
Findings presented under themes with no data presented as evidence. No data triangulation seen. Researchers have not discussed their background, training, relationship with participants and their preconceptions. Not clear what questions were asked. Development of questions is not described. Neither was it piloted. Methodologically weak study, measures of rigour not clear Lots of data with minimal evidence. Most findings about team functioning presented in other articles related to Rivermead and NRU.															
(Rohde *et al.*, 2012)	√	√	√	x	√	√	√	√	x	x	√	√	√	√	√
Member checking was done. Not sure if analyst triangulation was done. Recruitment of patients was through participating SALT which might be biased in itself. Researcher has not discussed her background, training, and relationship with participants and her preconceptions. Methodologically good study, however measures of rigour not clear. Findings about differences corroborate with goal differences from other studies. Relevant to UK practice.															

(Playford *et al.*, 2000)	x	x	√	x	x	x	x	x	v	x	x	x	x	x	x
This seems like an opportunistic paper. What if the scribe had made interpretations during note-taking; it is hard to listen and take notes while people are discussing and cannot cross check as no recording was done. Workshop discussions were scribed and written up. Methodologically weak study, measures of rigour not clear. Lots of description with no evidence. Some relevant to UK practice. Specialist centre practice has been described. Not applicable to wider settings.															
(Parry, 2004)	√	√	√	x	√	-	√	√	x	x	√	√	√	√	√
Methodologically good study, however measures of rigour not clear. Lots of interpretation with minimal evidence. In-depth analysis of interaction which corroborates with other research. Relevant to UK practice.															
(Lloyd, Roberts and Freeman, 2014)	√	√	√	√	√	x	√	√	√	x	√	√	√	√	√
Single method representing one perspective. The interview and data collection was evolving based on the approach. Researchers have not discussed their background, training, preconceptions and relationship with participants is not clear. Data and themes clearly linked. However, these are very descriptive. They suggest empowerment for collaborative GS but diagram links education to therapist lead GS. Needs further clarity of findings presented here. Explains the methodology clearly. Single method, no triangulation. High chances of social desirability. Context very relevant to UK practices. Gives understanding of discourse, but not needs further research to convert this knowledge to be more applicable to change practice even though what they call a toolkit is just strategies which do not seem to be adequately drawn from the data. Example education of patient does not come from data. What does this mean?														
(Levack *et al.*, 2011) (Levack *et al.*, 2009)	√	x	√	√	√	√	√	√	√	√	√	√	√	√	√
Data saturation is discussed. No member checking reported.															

Naturalistic data collection. Inclusion exclusion does not specify communication issues. Families represented some patients which may not be ideal. Explains the methodology clearly. Some context maybe different from UK practices. E.g asking patient and family for goals using structured questionnaire is not common in UK. Gives understanding of discourse, but not needs further research to convert this knowledge to be more applicable to change practice.															
(Leach *et al.*, 2010)	√	√	√	√	√	x	√	√	√	x	√	√	√	√	√
Development of questions is not described. Neither was it piloted. Researchers have not discussed their background, training, relationship with participants and their preconceptions. Minimal quotes presented for a huge amount of interpretation. Yes multiple reminders and use of emails to get data from busy staff. Reflection was supposedly encouraged. However, more chances for social desirability in responses. Methodologically good study, however measures of rigour not clear. Lots of data with minimal evidence. Some interpretations not supported by data. Purpose of classifying goals is not clear. The facilitators are basically perceived advantages of the process. Cleverly used implicit questioning about patient centredness.															
(Lawler *et al.*, 1999)	√	√	√	√	√	√	√	√	√	x	√	√	√	x	√
Data saturation is not discussed. No member checking reported. Not clear where the interviews were done. Methodologically good study, relevant to local practice. GS has to be done with sensitivity and flexibility, reference for recovery for nurses is different from patients' point, not impose goals but develop working relationship, ask for hopes and expectations (to embed reality)															

(Laver *et al.*, 2010)	√	√	√	√	√	x	√	√	√	√	√	√	√	√	√
Tool was not piloted; developed by researcher and team based on literature. However, most participants found goal to be a difficult term to understand – this could have been overcome if tool was piloted. Only major themes were presented. Negative cases were not discussed. No member checking reported. Second analyst helped to derive themes (she did not code but cross checked codes- immersion in data not possible) The documented goals were shown to patient to see if they recalled them but they did not, which reflects badly on the treating therapists. Since the therapists were known to the researcher as a colleague. They should have just asked patients what goals were set by professionals for them. Methodologically good study, relevant to local practice. However, some reliability issues such as different question/ wording of questions at different stage shows previous assumptions of researcher that those patients might not be ready to contribute to GS in the acute stage. This was proved true according to their findings.														
(Huby *et al.*, 2004)	√	√	x	x	√	x	√	x	√	x	√	√	√	x	x
Not discussed details of approach. There is no information about recruitment strategy. No clear inclusion criteria. No reasons for why patients did not participate. No information on what questions were asked, piloting, reliability of interview guide. Researchers have not discussed their background, training or their preconceptions and relationship with participants. Data saturation is not discussed. No member checking reported. Compared notes about interviews with second researcher. No other details provided. But lot of information from literature included in the interpretation of results. So it is confusing which of the findings researchers' interpretations in this study are. The study lacks methodological rigour. Limited information about the research process. But the context has been explained well and hence seems relevant to local practice. The study is not about GS but researchers have reported on rehabilitation GS from the findings. Though not relevant to their aim it was found relevant to review and hence included. With thick description of cases it is possible to relate to local practice, but methodological weakness is a major concern.														

(Holliday, Ballinger and Playford, 2007a)	√	√	√	x	√	√	√	√	x	x	√	√	√	√	√
Explains the methodology clearly. Has employed good rigor strategies. Researchers have not discussed their background, training, preconceptions and relationship with participants is not clear. Data saturation is not discussed. No member checking reported. The categories and sub categories do represent the data and not logically linked. However heterogeneous group with number of stroke representation ot known. Relevant to UK settings. Intervention clearly described. No audit trail provided. Adequate information is not provided regarding who recruited and the inclusion criteria.															
(Hersh *et al.*, 2012a)	√	√	√	x	x	x	x	√	√	√	√	√	√	√	√
This study is methodologically rigorous, large scale study, embedded in theory, with context relevant to that of local practice. Does not specifically look at PCGS. No information about interview tool. Data saturation is not discussed. There is no information about recruitment strategy. No inclusion criteria. Wide sampling across different states in Australia, different settings, wide work experience and large numbers of therapists involved															
(Henshaw *et al.*, 2011)	√	√	√	√	x	x	x	x	X	x	√	x	x	x	x
Author suggests that setting patient relevant goals to be trained by a cognitive approach helps motivate patient, reduces frustration and enables perseverance. Limited information on data analysis. Weak methodology relevant to the qualitative aspects of the study. Hence unreliable findings. No information on interview questions, what was observed from video or field notes. No data saturation discussed. No reflexivity on the part of the researcher except that she was a PhD student which might have biased the interpretations from the interviews. No testing of questions, where they came from etc.															

(Hale, 2010)	√	√	√	√	√	x	√	x	√	x	√	x	√	√	√
Findings presented under themes with data as evidence. Only major themes were presented. Minor aspects were not discussed. Different methods within interviews with 4 four therapists. There may have been different limitations to each interview method. No audit trail. Based on the methodological rigour study is good and hence results may be reliable. Study does not look at PCGs but suggests GAS might be useful; two therapists' opinions are reported. No further indepth exploration of these opinions. Further there are many disadvantages described. Need to weigh the usefulness against the disadvantages with the use of GAS.															
(Hale and Piggot, 2005)	√	√	√	√	√	x	√	√	√	x	√	√	√	√	√
Recruited through managers. Whether there was pressure is unknown. Researcher might have biased the design of the question guide. No data saturation discussed (repeat interviews were not possible due to distance between centres). Not piloted or cross checked. Based on the methodological rigour study is good and hence results may be reliable. Study does not look at PCGs but suggests therapists in HBSR favored patient centred approach to GS and involved patients in setting goals. All participants said they used achievement of patient goals as success of their therapy. No further in-depth exploration of these opinions.															
(Gustafsson *et al.*, 2014)	√	√	√	x	√	x	x	√	√	x	√	√	√	x	x
Not clear how therapists were recruited to the STRENGTH program. Researchers have not discussed their background, training. Relationship with participants is not clear. Information about data collection process is limited. Development of questions is not described. Neither was it piloted.															

(Guidetti and Tham, 2002)	√	√	x	x	√	x	x	√	x	x	√	x	x	√	x
Researchers have not discussed their background, training, preconceptions and relationship with participants is not clear. Data does not relate to themes in some places. Descriptive data analysis where themes and subcategories are not linked. Repetitive data. Inadequate data too much interpretation without support. Data did not produce direct strategies for practice since professionals took it for granted that were imbibed in practice. Observations would have helped gain a better perspective or added to this data. Adequate information is not provided regarding who recruited and the inclusion criteria and participant characteristics. No audit trail. No valid tool used. Open ended interviews not piloted. Not clear how the tool was developed. Single data source. Information about interviewer is not clear. Data saturation is not discussed. No member checking reported. The categories and sub categories do represent the data and not logically linked. Overlapping themes and subthemes. Data repeated. Explains the methodology clearly. Rigour lacking. The context of study is clear and relevant to UK practice. But the researcher has not explicitly studied goals. In one aspect of OT practice clients are assisted to set goals by letting them try out, take control and their expectations are managed early when setting goals. Methodological and reporting weaknesses present.															
(Daniels, Winding and Borell, 2002)	√	√	√	√	√	x	√	x	√	√	√	√	√	-	
Where data was collected is not clear. In places the author mentions semi-structured interview which is confusing. Actual data collection was using FG. No audit trail provided. Data saturation is not discussed. Only major themes were presented. Negative cases were not discussed. The study is grounded in theory of occupational therapy. They do not have home visits in their practice to create awareness of limitations for the patients. However, in UK whether OTs utilise their home visits for this purpose (setting meaningful goals) is not clear. OTs report being protective, identified in other professional literature too.															
(Cott, 2004)	√	√	√	x	√	√	√	x	√	√	√	x	x	√	√

There is no information about recruitment strategy. Sampling is stated as theoretical with no explanation of how it was done. Clear inclusion criteria. Where data was collected is not clear. All patients had chronic disability and had undergone rehabilitation from the public provider. Questions were generic, not piloted and did not ask directly about what patient-centredness meant to them. No audit trail provided. Data saturation is not discussed. No member checking reported. Second analyst derived themes (she did not code but cross checked codes- immersion in data not possible) Only major themes were presented. Negative cases were not discussed. Quotes from patients relate to interpretation. But lot of information from literature included in the interpretation of results. So it is confusing which of the findings are from the participants in this study. The study is grounded in theory. However, the steps in recruitment, and rigour (researcher's biases, wide population, saturation, audit trail) are not explained and hence quality of methodology could not be judged effectively. The context of study where and who did it is also not clear. Hence transferability and researcher bias cannot be eliminated. However, the findings give insight into how patients think regarding goal-setting for rehabilitation. One group was stroke but it has to be assumed that findings adequately represent the stroke patients' views in this study.														
(Brown *et al.*, 2014)	√	√	√	√	√	√	x	√	√	√	√	√	√	x	√
No member checking reported. Tool was not piloted; Methodologically good study, partly relevant to local practice. COPM is not regularly used for exploring patient goals. However, some reliability issues such as questions not being known. Single method of data collection-no triangulation done.															
(Boutin-Lester and Gibson, 2002)	√	√	√	√	√	√	x	√	√	√	√	x	√	√	√
They only suggested that OTs were collaborative in setting goals based on patient responses. However, what were their goals and what was recorded cannot be corroborated. Data saturation is not discussed. The duration of interviews is not known. Information about interviewer is clear. Negative case analysis has not been done especially since there were cases who did not fit the profile (one who was unhappy with negative experiences) triangulation using another method or data saturation would have helped strengthen findings.															
(Bendz, 2003)	√	x	x	√	√	x	√	√	x	x	√	x	x	x	x

It is a Phenomenographic study, but the phenomenon under scrutiny is not clear as the questions that were asked are not given. Data about professionals' perspectives were collected from documents which cannot explain understanding of professionals (opinions/views will not be recorded) but only superficially describe practice. Comparing just these two data sources is not appropriate to see similarities and differences. Tool was not piloted and it is not clear how it was developed. Three points of data collection was done. The duration of interviews is not known. Document summarisation is briefly described. Information about interviews is clear. No audit trail provided. Data saturation is not discussed. No member checking reported. The categories and sub categories do represent the data and not logically linked. Researchers have not discussed their background, training, preconceptions and relationship with participants is not clear. Data does not relate to themes in some places. Descriptive data analysis where themes and subcategories are not linked. Quotes from patients do not relate to interpretation in places. Interpretation of goal-differences based on data not from explicit questioning. Data collection about professionals' views was not appropriate using case notes. The context of study is clear and relevant to UK practice. But the researcher has not explicitly studied goals. She has only suggested that patient goals and professionals' goals maybe different based on the data. Limited rigour strategies adopted except for data triangulation.															
(Alaszewski, Alaszewski and Potter, 2004)	√	√	√	√	x	x	x	x	√	x	x	√	√	√	√
There is no information about setting in which study was conducted, recruitment strategy, sampling or clear inclusion criteria. Tool was not piloted and it is not clear how it was developed. No repeat interviews for data saturation done. Interviews were tape recorded. Duration of interviews not known. Information about use of diaries is absent except in the abstract. Who collected data, duration of data collection and their training have been missed. Whether it is error in reporting or methodology is not clear. No audit trail provided. Researchers have not discussed their background, training, preconceptions and relationship with participants is not clear.Ethical approval from committee is not mentioned. Consent and withdrawal were not discussed.															

	Template to Assess Quality.
√- Indicates positive quality aspect x- Indicates negative quality aspect - -Not relevant	1. Clear Aims 2. Adequate background 3. Appropriate design and methodology 4. Appropriate recruitment strategy 5. Appropriate data collection methods 6. Reliable and valid data collection tools 7. Adequate description of data collection methods 8. Adequate description of data analysis steps 9. Reliability and validity in data analysis attempted 10. Reflexivity 11. Ethical issues 12. Findings clearly presented 13. Data analysis was grounded in the views of participants 14. Appropriate methods to encourage participants to express their views 15. Value of research

Appendix 2.8 Sample analysis of findings from qualitative studies in the process of deriving themes

Author, year and Setting	Aims and Objectives	Findings	Codes	Categories
(Bendz, 2003) Stroke unit Sweden	To understand how people who have had a stroke and their health care professionals understand the implications of a stroke and the rehabilitation process after it.	The aim of the stroke patient was to regain former social position or adapt to another position to avoid demands involved in their former social position. Patients believed that training to achieve their goals will help change their situation. For the professionals the aims of rehabilitation was to improve functions of the patients. No structured goals were expressed by patient or professional. No strategies were written to achieve patient goals.	Regain social identity Gain new identity Training for goal achievement. Professional goals functional Lacking structured goals Lacking strategies for goal-achievement	Survivor's context for goal-setting Professional principles for goal-setting Ineffective goal-setting
(Boutin-Lester and Gibson, 2002)	To explore and report patients'	All participants reported that process of goal-setting was collaborative.	Collaboration in goal-setting	Principles of PCGS

Community USA	perceptions of home health occupational therapy.	They all expressed goals for therapy but some were general goals. If specific goals were expressed then they were accommodated by the OT. Contrary to goal-setting the treatment options were decided by the OT and were done by OT to the patient.	Patient goals-generic Specific goals accommodated Intervention for goals decided by professional Interventions done to patient.	Conflicts in PCGS

References:

Bendz, M. (2003). 'The first year of rehabilitation after a stroke – from two perspectives'. *Scandinavian Journal of Caring Sciences,* 17**,** 215-222.

Boutin-Lester, P. & Gibson, R. W. (2002). 'Patients' perceptions of home health occupational therapy'. *Australian Occupational Therapy Journal,* 49**,** 146-154.

Appendix 3.1 Conceptual Analysis of the Patient-centredness concept

Background:

Patient-centredness is the foundational concept for this study. The review of literature (chapter 2) revealed that this concept has been variably defined, interpreted and adopted in research and practice. It was clear that patient-centredness was a multidimensional concept with several aspects representing each dimension. Despite this complexity, there was an increasing impetus to deliver care processes based on a patient-centred approach; a multitude of research looking at health care processes using this approach reflected this drive. However the lack of understanding of its complexity had led to researchers to apply and study isolated facets of this concept. This raises concerns about mis-interpretation of the meaning of the approach used within a study due to the use of an umbrella term rather than indicating the singular constructs within this broader approach. Thus it was considered essential to clarify the meaning and intended use of this patient-centredness concept at the outset of the research to avoid similar dilemmas in the interpretation of this research.

Purpose:

An analysis of the meaning of the concept was proposed for the following reasons:

- To examine the complexity of the concept by identifying its multiple dimensions and components that are considered to fit within these dimensions.
- To define the concept, its components and ensure a boundary for each of these constructs.

- To maximise the use of the entirety of the concept as relevant to the goal-setting process by setting out constructs in a simple, meaningful and useable format (A framework).

Method:

The steps involved in analysing the concept and setting up a framework for the purposes of this research involved the following steps:

- The literature derived from the systematic search (chapter 2) was screened for articles that had reviewed the concept or attempted to define the components of the concept. Only articles that described the concept in its entirety were shortlisted. Literature was collected with a multidisciplinary perspective since the process studied in this research (goal-setting) was multidisciplinary. Four papers from family practice, cognitive rehabilitation, physical rehabilitation and nursing were included.
- The components of patient-centredness defined within each of these articles were drawn out and listed. There were several overlapping components (different terminology for same purpose) identified within the literature. The commonalities were merged and repetitive components were removed.
- The resulting list included discrete components relevant to health care processes in general. Some of them could not be studied within a goal-setting process and therefore filtered from the list.
- The four major dimensions which were broad enough to encompass other dimensions were identified from the key literature (Mead and Bower 2003). These were set out as dimensions for this the framework. Following this the components that fit within

these dimensions from all literature were arranged underneath these dimensions. (Table 1)

- Each of these dimensions and components were defined from the literature to ensure clarity of constructs within this concept.

Use of this framework:

The frame work was set out to understand the comprehensive constructs within patient-centredness. Rather than using the concept loosely, it was decided to study the goal-setting process using this approach based on the entire complexity of the concept and was used in the following ways.

- Research questions that explored what participants interpreted this concept to be, how they used it and what they thought its outcomes were.
- Further the conceptual framework was used to explore the presence of the various elements within the data and practice.
- When a method was applied for patient-centred goal-setting the evaluation of this method and improvement in practice included the evaluation of the components in a comprehensive manner using the framework.
- Interpretations and conclusions, to an extent, were drawn based on the identified components of patient-centredness to embed findings within theory and avoid theoretical reinvention.

Table 1: Revised framework after screening, shortlisting and integrating relevant components.

Dimensions	Components
Bio-psychosocial perspective **HOLISTIC**	• Biological problems • Psychological issues (Recognition and management of emotional needs) • Health promotion • Carer or family involvement • Social/ • participation issues - Education/work/leisure • Economic situation • Transition & continuity of care- Transition : Hospital→home& Living in the community –Ongoing help with care giving • Environmental- Understanding of patient living conditions- Intervene with environment with routines close to patient (Family, carers etc)
INDIVIDUALISTIC	• Biography (life setting explored) • Subjective experience-Personal meaning of illness for patient/ Attitude to illness • Understanding of his psychological world and motivation in presentation • Emotions-Fear/Feelings/ Conflicts • Context and time sensitivity- Needs vary in context and magnitude • Personal relevance- Relevance to daily life/ /Personally relevant outcomes/ Methods and criteria for success
Empowerment **Sharing responsibility**	• Patient as expert→Greater recognition of lay knowledge, competencies and experience/ Consensus through negotiation (Involvement in decision making) → Expression of values, preferences & needs -Above need to be explored and understood Respect for patient autonomy→Adequate information and explanation (right to info)

	→Provide assistance when new skills or resources are required. • Ongoing information exchange that is Multidirectional/ • Empowerment in community/ Modern technological opportunities-(encourage behaviour/interaction to seek help & interaction) • Patient as active problem solver • Strengthen existing problem solving skills • Develop new functional abilities and coping abilities (**Habilitation**) • Executional autonomy • Active participation →Participation in goal formulation; Subjective preference/ significance of outcome/ weight of each • Informational control • Decisional control/ Decisional autonomy (Choices, action plans, information) • Self efficacy beliefs
Therapeutic relationship	Positive emotional responses affect improvement Congruence: Perceives relevance →Common understanding of goals and requirements of treatment/ Agreement for goals • Clinician attitudes: Therapist shows Empathy, Unconditional positive regard and Patient sees Dr as Caring/Empathetic/Sensitive • Need to maintain hope i.e. Positive perspective • Bonding →Treating people with respect and dignity • Professional respect→Rights to moral respect, participation in democracy & interdependence

Definitions of the dimensions and components

I. **Biopsychosocial approach** posits that biological, psychological (which entails thoughts, emotions, and behaviors), and social factors, all play a significant role in human functioning in the context of disease or illness. Indeed, health is best understood in terms of a combination of biological, psychological, and social factors rather than purely in biological terms

Biological component of medicine suggests disease process can be explained in terms of an underlying deviation from normal function such as a pathogen, genetic or developmental abnormality, or injury.

Psychological pertains to the aspects of health that arise from the mind such as affective or cognitive functions and entails thoughts, emotions and behaviour

Social pertains to the interaction of the individual to the group or the society.

Health promotion is the process of enabling people to increase control over their health and its determinants, and thereby improve their health". Health promotion strategy is "aimed at informing, influencing and assisting both individuals and organizations so that they will accept more responsibility and be more active in matters affecting mental and physical health"

Carer or family involvement pertains to giving information, emotional support and exploring the biography of the patient and seeking their involvement in goal setting or decision making for care.

Economic situation- understanding of how patient manages financial resources

Participation issues relate to functioning of individuals in social situations, home life, education, work and economic life.

Environmental conditions within the rehabilitation setting and unique environment in the community need to be understood in order that the environment can be modified for the individual rather than the other way around. It includes modification of the interaction between interdependent individuals to reduce stigma of illness.

Leisure

Transition and continuity of care relates to the steps taken during hospitalisation to enable them to independently function at discharge and in the community. This may involve practical support such as help with everyday activities, knowing where to find resources, gain access to resources and services.

II. **Individualistic approach** relates to the view of approaching patients as individuals with individualistic assessment of patients' needs and tailoring intervention based on that, rather than routine or standardised approach.

Biography pertains to the exploration of patient's personal history of life and its setting.

Subjective experience is exploring the personal meaning of illness for the patient in order to understand the effect of illness and his attitude towards the illness.

Understanding his psychological world would involve understanding the wider psychological context such as the motivations of the patient's presentation, values, motives in life, preferences.

Emotions would be his affective reactions and thoughts of fear, feelings and conflicts as a result of his illness.

Sensitivity to time and context would involve an awareness not just of the current situation but the varying needs over time in hospital and other contexts such as home and work.

Personal relevance would indicate that the goals and intervention are relevant to patient's daily life and outcomes reflect this and are hence measured using personally relevant methods and success criteria.

III. **Empowerment and sharing responsibility** is the aspect of enhancing the patient's potential to participate and the patient is more active rather a passive recipient of care.

Active problem solving patient would be where the patient would be able to put forward problems, prioritise them, reason out and seek solutions for the problems.

Strengthening existing problem solving skills would involve the professional who assists in breaking down the problem; suggest solutions or alternatives and resources.

Ongoing multi-directional information exchange would be the flow of information between various parties which is flexible in content, magnitude over time and extends into the community.

Informational control is the ability of the patient to get required information about their condition in order to gain control over their situation.

Self-efficacy belief is a cognitive behavioural mediator through which patient perceives that he is capable of achieving positive outcomes by carrying out certain behaviour or the belief that they possess the required skills to achieve the required outcomes.

Active participation in this context would mean that the patient would actually identify his needs, personally relevant goals, prioritise their significance and that of the

outcomes and record his progress in goals either on his own or collaboratively with the professional.

Habilitation is the approach with a focus on future orientation which considers the resources, patient abilities and strengths to build **new** functional, social and emotional abilities rather than just trying to regain what was lost.

Executional autonomy is the ability of the patient to carry out his decisions or delegate actions which are oriented to his priorities.

Decisional autonomy is the ability of the patient to make appropriate decisions based on the choices and information available and make action plans.

Decisional control is the ability of the patient to make the appropriate decision relevant to their problem and within their unique context based on their knowledge, information recieved and skills.

Patient as an expert would indicate that the professional acknowledges lay knowledge, experience, and expertise and encourage patients to voice values, preferences, needs and ideas, listen to them and offer opportunities for them to collaborate.

Respect for patient autonomy would entail respecting their need for independence and therefore providing opportunities in the form of information that facilitates understanding of activities (interventions/ actions) for independence in everyday context and also provide assistance when they need new skills or resources.

Empowerment in community: Encourage behaviour/interaction to seek help with care in the community.

IV. **Therapeutic relationship** is the aspect of patient centeredness concept that is based on the cognitive theories that positive emotional influences can affect

improvement. Hence it is the requisites for an alliance between patient and professional that endeavours to establish this positive emotional response.

Clinician attitudes of caring, empathy, sensitive as perceived by patient and clinician showing positive regard for the patient have been suggested as requirements for therapeutic alliance.

Bonding is the establishment of a personal bond between the patient and professional where they treat each other with respect and dignity.

Professional respect for the patient's right to moral respect, participation in a democratic process and interdependence as normal.

Maintaining positive hope is the need for the professional to help patient maintain the positive perspective in all situations.

Congruence is the perceiving of relevance of goals by both parties and hence they have a common understanding of goals and interventions and agree with the goals.

References

Leplege, A., Gzil, F., Cammelli, M., Lefeve, C., Pachoud, B. & Ville, I. (2007). 'Person-centredness: Conceptual and historical perspectives'. *Disability and Rehabilitation,* 29**,** 1555 – 1565.

McCormack, B. (2003). 'A conceptual framework for person-centred practice with older people'. *International Journal of Nursing Practice,* 9**,** 202-209.

Mead, M. & Bower, P. (2000). 'Patient-centredness: a conceptual framework and review of the empirical literature'. *Social Sciences and Medicine,* 51**,** pp.1087-1110.

Ozer, M. N. & Kroll, T. (2002). 'Patient-Centered Rehabilitation: Problems and Opportunities'. *Critical Reviews in Physical Rehabilitation Medicine,* 14**,** 273-89.

Appendix 3.2 Evidence for Patient and Public involvement in research processes

Advice to improve the Patient goal setting workbook

brin.helliwell@googlemail.com

Sent:27 June 2013 13:39

To: Sheeba Rosewilliam [s.b.rosewilliam@bham.ac.uk]

Hi Sheeba. I'm really pleased to hear that you have decided to go back to plan A, and separate the 2 patient documents. I've had a look at the workbook and it looks good but i would Advise you to consider the following amendments to improve the Patient goal setting workbook .Some of the language used is quite complex, as you use an elaborated code when a restricted code may be more appropriate for the average stroke patients needs? But try it as it stands and see if it works first.

i would also suggest that you change the format of the introductory paragraphs

It is much easier to read this information if it is in a larger font and listed in bullet points

I also wonder if it would be useful to state that; we understand that it may be difficult for you to set goals at this time as you do not know what is possible for you to achieve.?

eg.

1:We think it is important to take into consideration your needs and aspirations when we plan for your rehabilitation. 2:We also recognise the importance of understanding your personal situation for effective planning. 3:Therefore we would encourage you to contribute to this goal-setting process.

4:This work book is being given to you to make you think of your needs, plan your care and decide on your goals for rehabilitation.

5: We request you to think about the questions in your spare time and fill it in if possible.

6:What you record here will help you, your carer and your key contact person (KCP) to raise issues and clarify doubts with the other team members.

7:If you are unable to write then your KCP will fill it in for you. You can involve your family member/carer for filling in this workbook if you wish to.

I hope that you find these comments useful.

Oh and yes I am enjoying the warmer days. I had a week in France at the start of the month and as June has turned out to be generally warm, it's amazing to see the difference in my shoulder, arm and hand function.its given me a real boost in my motivation and belief that I can still make significant improvements.

Regards,

Brin

Appendix 4.1 a..... Ethical Approval for Study one

The Black Country Research EthicsCommittee
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Redditch
Worcestershire
8976EW

Telephone:

Facsimile:

26 November 2010

Mrs Sheeba Rosewilliam
Lecturer
University of Birmingham
School of health and population sci
University of Birmingham
No.52 Pritchatts road, Edgbaston
B15 2TT

Dear Mrs Rosewilliam

Study Title: "The influence of patient-centredness during goal setting in stroke rehabilitation – a study involving exploration of present practice and proposal for a patient-centred model for future practice."

REC reference number: 10/H1202/56

Thank you for your letter of 29 September 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I *am* pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form; protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approva/') should be sought from all NHS organisation(s) involved in the study in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System (IRAS) or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre'), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Protocol	v1	06 July 2010
Response to Request for Further Information		22 August 2010
Response to Request for Further Information		29 September 2010
Participant Information Sheet: PIS Staff	v1	22 August 2010
Covering Letter		22 August 2010
Covering Letter		29 September 2010
REC application		02 July 2010
CV Academic Supervisor		02 July 2010
Participant Information Sheet: PIS "tracked"	v2	28 September 2010
Interview Schedules/Topic Guides	v1	07 July 2010
Interview Schedules/ropic Guides	v1	06 July 2010
Evidence of insurance or indemnity		01 August 2009
Referees or other scientific critique report		01 April 2009
Summary/Synopsis	v1	06 July 2010
Investigator CV		02 July 2010
Participant Consent Form: Consent Patients	v2	22 August 2010
Participant Consent Form: Consent Staff	v2	22 August 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk .

[10/H1202/56 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Jenny Tyers (Mrs) for and on behalf of

Dr Jeff Neilson Chair

Email: jenny.tyers@westrriidlands.nhs.uk

Enclosures: "After ethical review - guidance for researchers"

Copy to: *Dr Brendan Laverty*

Appendix 4.1 b Research and Development approval

The letter is redacted from the e-thesis for confidentiality protection.

Appendix 4.2 a Participant Information sheet for patients for Study one

UNIVERSITY OF BIRMINGHAM

Study information sheet for patients-Version no.1

Study title: The influence of patient-centredness during goal setting in stroke rehabilitation- a study involving exploration of present practice and proposal for a patient-centred model for future practice.

Introduction

It is believed that if the patients are more involved in their care especially when planning for their rehabilitation, then they may be better motivated to participate. Thus the care needs to be 'patient-centred' rather than doctor centred. 'Patient-centred' care is that which is tailored to individual patients taking into consideration their needs and expectations. Currently there is insufficient guidance to implement patient centred practice in setting goals for their rehabilitation. Therefore this study aims to investigate how we can develop patient-centred good practice methods with the help of patients and staff for future practice. This research is part of a PhD project by the researcher. We invite you to take part in the project and to share your views with us.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part. We thank you for the time and effort spent on considering participation in the study.

Who is doing the study?

This is a research project done by the researchers from the University of Birmingham in collaboration with the University Hospitals Birmingham NHS foundation trust. Ms Rosewilliam, the researcher on this project, is a state registered therapist who teaches in the School of health and population Sciences at University of Birmingham and is carrying out this work as a part of a PhD program. Ms Carron Sintler is the stroke physiotherapy consultant on the

project and this program of work is being supervised by Dr.Carolyn Roskell from University of Birmingham and Dr. Anand Pandyan from Keele University.

Why this study?

The guidelines for health care professionals recommend that patient should be at the centre of care especially when planning for their rehabilitation. It is believed that patient-centred care may lead to better participation and therefore better recovery. In this study we propose to explore whether this guidance is followed in the hospital setup by all those involved and what are the difficulties in implementing patient-centred care. Furthermore since there are no definitive pathways to implement patient-centred care we would like to devise a model to enable patient involvement during setting goals for the patient.

Are you eligible to join the study?

All stroke patients who are medically stable and able fully to communicate within a week after their stroke are eligible to take part in this study. It is important to note that participation in this study is entirely voluntary and you are not obliged to support this study. The standard of care you receive or your legal rights will not be affected in any way if you do not wish to participate in this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason. A decision to withdraw at any time, will again not affect the standard of care.

What happens if you decide to participate?

If you decide to take part in the study you will be asked to sign consent forms. Then you will either be asked to do an interview with the researcher or participate in a group discussion with other patients or staff. During the interview you will be asked about your experience of stroke, care in the hospital and your involvement in care planning.

Participants in the focus groups will be asked to discuss issues regarding involvement in setting rehabilitation goals and how it can be done better. The researcher will also attend meetings where your goals are discussed to observe the interaction between the various staff and to study the process. It is important to know that you will only contribute either to the interview or the focus group.

At the time of signing up it will be made clear to you by the researcher whether you will be doing an interview or a focus group.

These interviews and focus groups will be tape-recorded and transcribed into written text. All information will be made anonymous and stored securely in the researcher's office.

Taking part in this study will not affect the care received in hospital for patients. The interview will take about 45-60 minutes. They will be scheduled at a time convenient to you. If you find it tiring then the session can be broken up into two or more sessions. If at any point you no longer want to take part, due to any reason, then the interview can be stopped at any stage. Again this will not affect your normal care that you receive in the hospital. The focus groups will have six - eight participants and will take approximately one and a half to two hours. Again this will be scheduled at a time convenient to you.

Are there any issues of confidentiality?

All your data will be stored on a secure computer. All personal data will be made unidentifiable before analysis. It will not be shared with any person other than the academic supervisors of the research. Published data will not include your personal details.

Why should I participate in the study?

Your contribution to this study is highly valued since it will determine the barriers for patient centred goal setting in stroke rehabilitation. Your views will help us to identify factors that can enable patient centred planning for rehabilitation. Your participation may not benefit your current rehabilitation planning process; but with the knowledge that you share with us we hope to develop a process that enhances rehabilitation practice for future patients with stroke.

Are there any risks?

Since this is a non interventional study there are no major risks associated with it. Sometimes the participant may become upset when discussing their condition.

Reassurance and psychological support will be provided if needed. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. It is important to note that there are no special compensation packages available.

What happens at the end of the study?

The data collected will be analysed and findings written up. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local trusts in the form of presentations and posters. If you would like to know the outcome of the study please feel free to contact the researcher involved and copies of reports will be sent to you. Anonymised data from this study will be used to support other similar research in the health field.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study. The research team wishes to thank you for giving your time in this time of stress whether you decide to participate in the study or otherwise. Thank you.

Contacts

1. **Sheeba B Rosewilliam**, School of health and population sciences, University of Birmingham, B15 2TT.

2. **Carron Sintler,** Consultant Physiotherapist for stroke services, Queen Elizabeth hospital, Birmingham.
3. **Dr. Carolyn Roskell**, Lecturer, School of health and population sciences, University of Birmingham , B15 2TT,

4. **Dr. Anand Pandyan**, School of Health and rehabilitation, Keele University, Keele ST5 5 BG.

Appendix 4.2 b ... Participant Information sheet for staff for Study one

Study information sheet for staff -Version no.1

Study title: The influence of patient-centredness during goal setting in stroke rehabilitation- a study involving exploration of present practice and proposal for a patient-centred model for future practice.

Introduction

It is believed that if the patients are more involved in their care especially when planning for their rehabilitation, then they may be better motivated to participate. Thus the care needs to be 'patient-centred' rather than doctor centred. 'Patient-centred' care is that which is tailored to individual patients taking into consideration their needs and expectations. Currently there is insufficient guidance to implement patient centred practice in setting goals for their rehabilitation. Therefore this study aims to investigate how we can develop patient-centred good practice methods with the help of patients and staff for future practice. This research is part of a PhD project by the researcher. We invite you to take part in the project and to share your views with us.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part. We thank you for the time and effort spent on considering participation in the study.

Who is doing the study?

This is a research project done by the researchers from the University of Birmingham in collaboration with the University Hospitals Birmingham NHS foundation trust. Ms Rosewilliam, the researcher on this project, is a state registered therapist who teaches in the School of health and population Sciences at University of Birmingham and is carrying out this work as a part of a PhD program. Ms Carron Sintler is the stroke physiotherapy consultant on the project and this program of work is being supervised by Dr.Carolyn Roskell from University of Birmingham and Dr. Anand Pandyan from Keele University.

Why this study?

The guidelines for health care professionals recommend that patient should be at the centre of care especially when planning for their rehabilitation. It is believed that patient-centred care may lead to better participation and therefore better recovery. In this study we propose to explore the difficulties in implementing patient-centred care. Furthermore since there are no

definitive pathways to implement patient-centred care we would like to devise a model to enable patient involvement during setting goals for the patient.

Are you eligible to join the study?

All staff who care for stroke patients from the different professions are eligible to participate. It is important to note that participation in this study is entirely voluntary and you are not obliged to support this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason.

What happens if you decide to participate?

If you decide to take part in the study you will be asked to sign consent forms. You will be requested to contribute to the research by participating either in the interviews or focus groups. During the interview you will be asked about caring for a stroke patient and planning for their rehabilitation.

Participants in the focus groups will be asked to discuss issues regarding involvement in setting rehabilitation goals and how it can be done better. The researcher will also attend meetings where goals are discussed to observe the interaction between the various staff and to study the process. It is important to know that you will contribute either to the interview or the focus group only. At the time of signing up it will be made clear to you by the researcher whether you will be doing an interview or a focus group.

These interviews and focus groups will be tape-recorded and transcribed into written text. All information will be made anonymous and stored securely in the researcher's office.

Taking part in this study will not affect staff performance reviews. The interview will take about 45-60 minutes. They will be scheduled at a time convenient to you. If at any point you no longer want to take part, due to any reason, then the interview can be stopped at any stage. The focus groups will have six - eight participants and will take approximately one and a half to two hours. Again this will be scheduled at a time convenient to you.

Are there any issues of confidentiality?

All your data will be stored on a secure computer. All personal data will be made unidentifiable before analysis. It will not be shared with any person other than the academic supervisors of the research. Published data will not include your personal details.

Why should I participate in the study?

Your contribution to this study is highly valued since it will determine the barriers that limit focusing the care on the patients. Your views will help us to identify factors that can enable

patient involvement and for patients to be at the centre of focus while planning for rehabilitation. With the knowledge acquired we hope to develop a process that improves clinical practice in future stroke rehabilitation.

Are there any risks?

Since this is a non interventional study there are no major risks associated with it. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. It is important to note that there are no special compensation packages available.

What happens at the end of the study?

The data collected will be analysed and findings written up. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local trusts in the form of presentations and posters. If you would like to know the outcome of the study please feel free to contact the researcher involved and copies of reports will be sent to you. Anonymised data from this study will be used to support other similar research in the health field.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study. The research team wishes to thank you for giving your time whether you decide to participate in the study or otherwise. Thank you.

Contacts

1. **Sheeba B Rosewilliam**, School of health and population sciences, University of Birmingham, B15 2TT.

2. **Carron Sintler,** Consultant Physiotherapist for stroke services, Queen Elizabeth hospital, Birmingham.

3. **Dr. Carolyn Roskell**, Lecturer, School of health and population sciences, University of Birmingham , B15 2TT,

4. **Dr. Anand Pandyan**, School of Health and rehabilitation, Keele University, Keele ST5 5 BG.

Appendix 4.3 a ..Consent form for patients for Study one

UNIVERSITY OF BIRMINGHAM

School of Health and Population Sciences

CONSENT FORM FOR PATIENT-Version No.2

Study title: The influence of patient-centredness during goal setting in stroke rehabilitation- a study involving exploration of present practice and proposal for a patient-centred model for future practice.

(Please tick either yes or no and add your initials in each box)

I confirm that I have read the information sheet about this study. I confirm that I understand the above information sheet about this study. I confirm that I have had the opportunity to ask questions about this study to ……(Name of applicant contacting the subject) and that all my questions have been satisfactorily answered.	Y/N
I understand that staff involved in the study may examine those sections of my medical notes that are relevant to my taking part in research. I give permission for these individuals to have access to my records	Y/N
I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study.	Y/N
I agree to take part in this study. I agree to direct anonymous quotations being used. I want to see any quotations before they are used. I permit the use of anonymous data from this study to support other research projects.	Y/N Y/N Y/N Y/N

.....	.....	
(Patient name)	*(Patient signature)*	*(Date)*
.....	.....	
(Witness name)	*(Witness signature)*	*(Date)*
.....	.....	
(Researcher name)	(Researcher signature)	(Date)

Appendix 4.3 b .....Consent form for staff for Study one

UNIVERSITY OF BIRMINGHAM

School of Health and Population Sciences

CONSENT FORM FOR STAFF- Version-2

Study title: The influence of patient-centredness during goal setting in stroke rehabilitation- a study involving exploration of present practice and proposal for a patient-centred model for future practice.

(Please tick either yes or no and add your initials in each box)

I confirm that I have read the information sheet about this study. I confirm that I understand the above information sheet about this study. I confirm that I have had the opportunity to ask questions about this study to …….(Name of applicant contacting the subject) and that all my questions have been satisfactorily answered.	Y/N
I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my legal rights being affected or compromised in any way. I am under no obligation to partake in the study.	Y/N
I agree to take part in this study.	Y/N
I agree to direct quotations being used.	Y/N
I want to see any quotations before they are used.	Y/N
I permit the use of anonymous data from this study to support other research projects.	Y/N

....
(Staff name) *(Staff signature)* *(Date)*

....
(Researcher name) (Researcher signature) (Date)

Researchers: Mrs. S B Rosewilliam, School of Health and Population Sciences, University of Birmingham, Edgbaston, B15 2TT. Phone: 01214142910/07872955548
Clinical contact: Carron Sintler, Consultant physiotherapist for stroke services

Appendix 4.4 Interview Question Guides for Study one

Patient Interviews-Question guide-Version No. 1- Date: 06.07.2010

1. What are the patients Goals?	Prior Status	1. Before your stroke what would you do in a normal week?
	Present Status	1. Do you miss anything from what you have told me? 2. Why is it important to you? 3. In what ways has the stroke affected you? 4. Why? / What can/can't you do? 5. When did you realise that the stroke has affected you the way it has? 6. What are your current needs in the hospital?
	Future Status	1. What would you like to do at the end of Rehab/ hospitalisation? 2. Why is it important? 3. Do you think it is realistic considering you have had a stroke?
2. How central is the patient in goal setting process?	Whether he feels central	1. Have you been consulted on your goals/ or on what you want to do in the future? 2. Who talked to you? / What was decided? /How was it decided? 3. Was there anything you needed to discuss and was unable to? Why? 4. Do you think your participation in setting your goals will help your rehabilitation and make your future better?
3. How to implement patient centredness in goal setting?	Barriers	1. What is that within you that stops you from contributing to setting your goals? 2. What factors in the hospital prevent you from contributing to planning your goals?
	Facilitators	1. Why do you think that you must be involved in setting goals? 2. Who/What encourages/motivates you to come forward and contribute to setting your goals?
	Strategies	1. How do you think you can involve better in setting goals and planning for rehabilitation? 2. How do think others can involve you better for planning your care and setting goals? 3. What more can be done to involve you better in setting your goals?

Professional Interviews-Question guide –Version No.1		
1. What are the patients Goals?	Understanding of pts stroke	1. Can you tell me how you come to know about a patient and his/her stroke? 2. Can you tell me about this patient's stroke? 3. What do you think are the needs of this patient? Is it important to know these and why?
	Present Status	1. What has been the impact of the stroke on this person's life? 2. What are you doing with this patient? Why?
	Future Status	1. What would you do expect this patient to do when he/she is better? 2. How did you decide on that? 3. What are you doing to work towards the above? 4. In general how do you predict what the patients will be able to do when they get better? 5. How do you plan for treatment and discharge for a patient?
2. How central is the patient in goal setting process?	Whether patient is central	1. Have you consulted patient on their goals or on what they want to do in the future? 2. Who else did you talk to? What was decided? 3. How was it decided? 4. Was there anything you needed to discuss and was unable to? Why? 5. What in your opinion is patient centredness in setting goals for a patient's rehabilitation? 6. Do you think patient's participation in setting goals will help rehabilitation and make recovery better?
3. How to implement patient centredness in goal setting?	Barriers	1. What is that within you that stops you from contributing to setting patient centred goals? 2. What factors in the hospital prevent you from planning patient centred goals?
	Facilitators	1. Why do you think that you must involve patient in setting goals? 2. Who/What encourages/motivates you to setting patient centred goals with your patients?
	Strategies	1. How do you think you can implement patient centred goal setting in current practice and in planning for rehabilitation? 2. What kind of systems could help you with this?

Appendix 4.5 .....Data extraction table for document analysis

Patient details	
Name of the document	
Authorship	
Structure	**General:** **Relevance to PCGS:**
Content	How Why What: When
Position of document	
Frequency of use	
Components of PCGS	

Appendix 4.6 ..... Focus group Topic Guide for Study one

Focus group-Topic Guide Version No.1-Date: 06.07.2010

Patient group

I. Understanding of Concept

1. What do you see as being at the centre of care?
2. Is it needed especially in terms of setting goals for rehabilitation? If so why do you think it is important?

II. Operationalisation

1. What do you consider as reasons within you that limit you from getting involved in setting goals and planning for your rehabilitation?
2. What do you consider as reasons that are external to you that limit you from getting involved in setting goals and planning for your rehabilitation?
3. How can you be better involved in planning for your rehabilitation and future?
4. What can help this goal setting process be focussed on you?
5. If we were to set up a new method of setting goals for rehabilitation with you at the centre of focus how would you like it to be done and what do you consider as essential requirements?

Professional group

I. Understanding of Concept

1. Is goal setting process relevant to acute stroke rehabilitation?
2. What do you consider as being a patient centred approach?
3. Do you think it is important to adopt this concept in the goal setting process? Why?

II. Operationalisation

1. What are the barriers to being patient centred in goal setting for rehabilitation for a patient in acute stroke ward?
2. Against the backdrop of current practice, with the above mentioned challenges what are the facilitators to adopt a patient centred model of setting goals?
3. If we have to set up a new model of patient centred goal setting within the limitations of current practice what do you consider as requirements- methods of practice and to influence behaviour of stakeholders

Appendix 4.7 Sample of data coding from Study one

		S: How did you come to know about F's stroke?
Prof per-condn- Info Ch.	Patient blanket referral Co-ord. referral	**L:** Because he came onto the ward. And then the stroke coordinator, L, told us about him. We had to go and assess him in 72 hours.
Prac. Sys-	Following guidelines Pt first contact	**S:** Okay. Can you tell me something about F's stroke?
Prof per-effects	Physical effects Spared higher functions	**L:** It affected the left side of his body, so it was a right MCA stroke with quite dense weakness. His main thing was the muscle power in his left side and sensation and things, but he was quite cognitive. He was quite with it and things, and his speech was not affected, so it was on left side.
		S: What were the needs of that patient in the hospital, can you remember?
		L: Medically or generally?
		S: Generally.
Prof per-condn.	Physical Medical issues Functional	**L:** I think he had some medical things; he had a few heart problems initially. We thought he had endocarditis and things, which might have caused stroke. So, he had a couple of medical things to sort out. He just needed a lot of rehab really. He had no sitting balance to start with, so he was in bed for quite awhile. We were trying to sort out an appropriate chair for him and then try and sort out his rehab.
Prof per goals	Pt Goal-sitting balance	
Chall to PCC	Resources for therapy	**S:** Why is it important for you to know his needs?
HOV	HOV Prof – Planning care delivery	**L:** To know his needs, so you know how to treat him, really I guess.
		S: So, how did you come to know about them?
Aspects of PCC ((Not assuming patient preferences) in NC's int.	Pt Involvement in GS Prof-Assess.	**L:** Through discussing with him, really, about what his main things were. Obviously we know what is wrong with him from an assessment point of view, but then I

Different here because NC doesn't ask patient but talks about establishing needs. Not mentioned as an ideal but has done it))	Exploring patient preferences/ needs Individualistic approach	suppose speaking to him and then finding out what things are most affecting him and what things he wants to get back to and things like that.
Prof per- effects Aspects of PCC	Disablement Explore pat pre-stroke status	**S:** What do you understand was the impact of the stroke on his life? **L:** He was disabled by it, really. So, he could not do anything for himself. He could not really feed himself, and he was _____ [1:53] really, so quite a big impact on his life. Before that, he was quite independent, I think. He was walking around with a stick, and I think he lives on his own. He was always quite upbeat about it; he did not seem to get too down about it and things. That was part of his personality; he always seemed quite happy, really. I think it obviously had a big impact on his life.
Prof per- effects Prof per-pat attributes	Positive Happy	**S:** So, what were you doing with F while he was here? **L:** Mainly looking at his shoulder. He had quite a bit of subluxation of his shoulder, so we turned that in the right position and made sure he didn't get any sort of pain in it. We were trying to do some flexing and keep range of movement in his upper limb and doing some active exercises with him, trying to get him to do something for his arm and his leg, and then looking at sitting balance and going to the gym, trying to get him sitting on his own, reaching out to get support and, and sitting him out daily in his chair. We were moving on to the tilt table, and then he went to Moseley Hall, so he didn't quite get around.
Prac. Sys- Interventions ((Prevention of complication Progress functional activity)) Prof per goals	Shoulder positioning Prevent pain Maintain ROM Active exercises Sitting balance Standing Arm function Sitting balance	**S:** Why were you doing all these things for

		him?
Prof per goals-	Improve muscle activity Get better	**L:** To try and get his muscles working again. To try to get him better, really.
		S: What do you expect him to do when he gets better?
Views on GS		**L:** It's hard to say, really, how much better, because he hasn't got any movement really in that side, so I think I will be a bit ambitious to say that he will regain all of his movement. But I think at least he has to be able to sit on his own. So, sitting balance will be quite a big goal for him. He can get out of bed by himself, sit on a commode, go into a shower and sit in a shower chair rather than just being in bed all the time. So, the main things is sitting I'd say, really. And then be able to use his upper limb a little bit more functionally and to maybe help him to feed himself and wash and dress himself.
Belief-pat. rec. Prof per goals-	Not entirely positive sitting balance Functional transfers Arm function Feed self Wash self Dressing	
		S: How did you decide on these things that you told me? How did you come to the conclusion that he is going to achieve these things? What makes you think so?
Views on GS Aspects of PCC Prof per Patient attributes	Decision Making Experience. Pt Involvement in GS Keen	**L:** Just really because of a bit of experience in terms of how much people are there and what he wants to achieve as well really, so having a chat with him and saying, "We could work on these, and you will be able to do this and this." He was quite keen on that, really.
		S: How did you plan for treatment discharge for this patient? You told you based treatment on assessment and experience. How about discharge – how did you plan for discharge?
Views on GS	Decision Making Intuition	**L:** We always knew he was going to Moseley because he needed a few months, really, probably more of rehab. So, he was never going to be able to go home from here. We didn't have to think that much because I knew he would just be continuing his rehab at Moseley, really.
	((Leading)) Decision Making	**S:** So, you thought he had the potential?

Chall to PCC Prof per Pat attributes Chall to PCC Prof per goals- Aspects of PCC Prac-System Views on GS	Potential for recovery Plateauing of recovery Conveying not asking Unrealistic Pt goals unrealistic Pt Goal-walking soon Guiding with goals ST goals better Prof-Prof Coll. Joint assessment Prof. goals	**L:** Yeah, he definitely was making some improvement, so he had some potential, but had to see where his end point was going to be would be I guess when he stops making improvement. **S:** Did you ask this patient where he wanted to go? Or did you ask him about his goals? **L:** In terms of what he wants to do after here? **S:** Yeah. **L:** Well, we sort of mentioned to him in terms of what happens normally, and he was quite happy with that, really. He lived around near Moseley, so he was quite used to it. **S:** Does he live in Moseley? **L:** He lived around there, I think. **S:** So, did you ask him what he wanted to achieve? Did he mention something that he wanted to do? **L:** He was a little bit unrealistic, really, he would sometimes say, "I'll be walking with my stick in a few weeks." I don't think was not really that realistic, so we had to lower the stakes. **S:** How did you convince him? **L:** Well, we had to say that it takes a bit more time, and he has to take little steps and set little goals rather than looking too far in advance. **S:** Did you have to talk to anybody else regarding his goals, to set his goals? **L:** We had a joint rehab with the occupational therapist as well, and they were working on similar things, but more functional things. They were sitting with him and doing washing, dressing, and stuff like that with him. So, we have similar goals, really, and it's kind of different approaches to try and achieve them.

Appendix 4.8 Sample of summary of data from documents from Study one

PC4					
Profession	**Event**	**What happens**	**Documentation of**	**Prof. Plan of Action**	**Rehabilitation goals**
No 1.	**Continuation sheet**				
SALT	Assessment		Sips thin syrup fluids and soft minced diet-	Frequent rests between mouthfuls. Stop if coughing. Plan to review swallow Plan: - review - check managing - to review - Discharge from SALT input- re refer if required.	
PT & OT					Sit-out recliner with hoist assist of 2 (nursing staff informed). Reduce sitting support as able/joint treatment with OT to improve function.
OT				functional assessment. Review on 15/8/11/ Continue	Plan: continue UL stretches/positioning Plan: as above MDT

				UL exs. To review UL exs/ continue UL exs/ functional assessment	goals/functional assessment/ UL work. Plan: continue UL work passive/stretches / positioning /assisted func. movements/ hand washing. Plan: UL work/find plate guard and knork (Taken by catering) - to complete Upper body W&D
Nurse				Pt needs help to sort out stair lift- Referral to SS	
Medical	WR	assessment, interaction with pat, Questioned about cough while eating and drinking,	Medical condition and vital statistics were noted IV fluid status noted Patient- urinary frequency. Heart and abdomen checked and recorded. - Medical condition and vital statistics were noted IV fluid status noted Investigation results noted - Medical condition and vital statistics were noted IV fluid status noted	Plan: Investigate urine/repeat ECG/Stop Abs/repeat bloods/echo to be requested. - continue Abs/repeat bloods - continue Abs/repeat bloods	

			Investigation results noted Muscle power assessed - Medical condition and vital statistics were noted IV fluid status noted Investigation results noted Muscle power /sensation assessed - Medical condition and vital statistics were noted Patient demeanour noted as chatty Investigation results noted Muscle power assessed - Medical condition and vital statistics were noted Patient complaints noted Investigation results noted - Medical condition/abdomen/vision/speech and vital statistics were noted Muscle power assessed	- stop Abs/continue therapy/consider warfarin/ venflow out/?MHH - Follow up Echo /continue therapy - consider warfarin/ Continue therapy	
		Advised Moseley hall as best option			

				- Drugs prescribed	
Recorded by student Physio.	Mini mdt meeting				Increase postural control in sitting Increase independence with washing and dressing Increase tolerance with washing and dressing Monitor swallow with a view to discharge
No.2	**OT neurological screening assessment**				
OT	Assessment				
No.3	**OT neuro assessment (diff from above)**				
OT	Assessment		Issues identified: Left sided weakness reduced function in UL/Reduced cognitive functioning/reduced eyesight	Further investigations into cognitive functioning/ assessment into sight.	Recommendations: UL work to increase functional work
No.4	**OT assessment sheet**				
OT	Assessment			further investigation into eyesight/ fatigue/ cognition-to identify a baseline	UL work on Left side to increase function and mobility of left UL/ Goals agreed with the patient: continue UL function to improve function/further investigation into eyesight/cognition

No.5	**MDT weekly sheet**				
MDT	MDT meeting	Discussion of patient status	Nursing –asks for toilet/feeds himself/needs help with washing and dressing PT: Dense LS Weakness/no sitting balance/follows commands/lt shoulder support. OT: Cognitive assessment/ engages well/strength UL/W&D practice SLT: Eating and drinking well		MDT agreed goals: Lt shoulder support/ Improve sitting balance/ W&D practice/ Potential for MHH Discharge destination?MHH
No.8	PT care programme record				
PT staff and students			Impairments-Hypotonia/ reduced awareness/reduced muscle endurance/reduced concentration/reduced postural control/subluxation of lt shoulder Activity: Reduced ability to roll/lie→sit/sitting balance/transfer bed→ chair/STS/Mobilise Participation: Reduced ability to perform ADL		**Goals agreed with patient column**: ST and LT states not yet assessed to assess on 4/8/11 On 17/8/11: Sit independently whilst washing and dressing 2/52 Physiotherapy Treatment goals on 3/8/11roll to left with min asst of 1 Achieved on 4/7 Edge sit on bed with min asst

		independently/socialise on returning home/unable to go shopping independently/unable to visit brother independently (lives close by).		of 1 Achieved on 4/7 Concentrate fully on therapy Achieved on 4/7 Roll to right with min asst of 1 1/52 Maintain Indep sitting balance 1/52 achieved 45 sec on 17/8/11 Sit → stand with asst of 1 1/52 Transfer with asst of 2 1/52 Maintain sitting balance >1 min 1/52

- SALT have more action plans and reviews than goals
- The OTs and PTs have short term impairment based goals
- Though their assessment identifies activity and participation limitations goals were not set at this level.
- There are opportunities to involve patient and record patient goals-E.g- goals agreed with patient; But they are either blank or the professionals' goals have been entered.
- Patient agreed goals are recorded but patient did not remember any of these in his interview.
- The MDT meeting records the patient's current ability and states goal as discharge to MHH which is only a discharge plan, not a rehabilitation goal.
- Drs. take care of everyday status of patient and state no goals other than about investigations, medications or referrals which are immediate concerns.

Appendix 4.9 Part of matrix for data display from multiple case-studies for Study one

	Biography	Subjective experience	Understanding of psychological world	Emotions	Personal relevance	Interpretations
PC1	PC1 was a software professional working with the BT. He was keen on DIY, played the guitar for a local band and played badminton on Tuesdays. He lived with his wife; his children were grown up and were staying away from home.	He ignored early symptoms and drove in to work next day. He couldn't recognise anything abnormal in the early stages of stroke. Ever since the stroke he had slowly started to realise what the effects of his stroke were primarily because he was attempting to do routine activities which highlighted his issues.	His motives in life were to enjoy life, achieve at work which he finds mentally stimulating, to relax and feel peaceful with his music and maintain a social life. He was confident and had exerted continuous effort to normalise speech.	He felt mentally weak due to his cognitive deficits. Emotionally he was unable to accept his stroke as he did not have risk factors such as high blood pressure or cholesterol. He was also frustrated that he could function as normal and felt a loss of control as result of his current condition. He was positive about the fact that he was still physically able.	He identified goals as wanting to be able to go back to work, play the guitar and regain IT skills. He had doubts whether he is being realistic and might not be able to return to exact pre-stroke status. In goal setting patients should be given opportunities to attempt routine activities in order to encourage identification of issues themselves which is better than if it was told to them.	

PC1 -OT		OT's assessment was the key step to understand patients' understanding of their condition.	With regard to this particular PC1 patient the OT branded him as "good patient" to work with due to his qualities such as being honest, motivated, forthcoming in his communication and felt comfortable working with him.	She suggested that the effect of PCGS was patient motivation.	OT considered the patient's current functional status and tended to compare this level of functioning with the patient's pre-morbid status before she decided goals. OT suggested that the patients seemed to have a different perspective on goals compared to that of the professionals. She said she was unsure of finer requirement for his IT job.	Here the patient wants to understand the steps to achieving the goal and OT thinks their goals are more like steps to the final goals. So the missing strategy is the explanation of this link between goals and steps towards these goals. Potentially then the professional will re consider her perceptions of that prof goal is different from patient's and that is a norm.
Field notes				OT mentioned psychological dysfunction that might have required intervention but had improved.		
Documents	Spirituality was not discussed though there is a scope in the document. Neither were leisure and meaningful activities recorded. Social status recorded as lived with wife, drove and worked prior to stroke.				WR-dr notes: Wife's concerns about texts were noted; SALT was to continue regarding texting. SALT records showed discussion with wife reporting about reading and writing. OT Goals agreed with the patient was **Blank** PT records showed Patient expectations section was left with a question mark	

Appendix 4.10 Example of a Summary Table to show different levels of congruence between different sources of data- Study one

PC3	Individualistic approach	Bio-psychosocial	Empowerment and sharing responsibility.	Therapeutic relationship
Reasonably good congruence	Staff was sensitive to the context and time after discharge. He said he had wanted her to be safe at home and normally involved social services at the point of discharge to care for the patient in the community. One staff was worried about her compliance with medications after discharge. Support from intermediate care was recorded in patient's notes. Patient wanted a communication channel which extended to the community.	Patient identified physical problems with her arm, sensation and balance. She raised this with doctor during rounds. Staff interviewed suggested that he understood her problems from notes and these issues were inconsistent in this particular patient. Doctors looked at her neurological and nutritional status during ward rounds and PT notes showed physical issues.		
Incongruent	Patient's subjective experience was that she was aware of her stroke but was scared due to her family	Multiple psychological issues were reported by the patient but were not picked by the staff caring for her.	PC3 had awareness about her issues but there were no instances of problem solving. She was keen to ask	Patient reported feeling scared to discuss issues and did not trust professionals. Staff perceived the patient to be

	history and risk factors. She realised her arm weakness and balance. But this was not recorded in the notes or during meetings. Staff did not voice her fears during the interview. An understanding of the psychological world of patient reveals her motives of caring for her family, a strong minded person but does not trust people easily. The staff however felt she was demanding and argumentative and was playing the system. The field notes showed that professional reported that she was weird since she was discharged.	Contrarily patient was reported as weird and demanding in meetings. Patient perceived this judgement about her; stated she did not want to participate so that she wouldn't be branded as awkward. Psychological issue of anxiety was recorded with no plans for it. Participatory issues such as driving, shopping and further education which was a life goal were raised by the patient but staff did not raise these in interview, meetings or in notes. Staff mentioned patient probably wanted to go back to nursing job which was not evidenced in any other source.	questions. Staff did not suggest any problem solving done with patient. The records and meetings did not involve problem solving with patient. There were no instances where patient was helped to problem solve. Self-efficacy was facilitated by the patient's family as mentioned by patient. But staff did not discuss patient's confidence in meetings or record in notes. Executional autonomy was witnessed in this case by the patient walking alone to the toilet reported by the patient and in the nursing notes. However patient suggested she was not supposed to go	confused and argumentative. So there was no evidence of bonding. OT records showed Patient agreed goals were Blank PT records showed Patient expectations section as NAD. No congruence in goals perceived. Patient perceived disrespect from staff when she was woken up loudly. She did not find some staff trustworthy. MDT discussed patient as weird and demanding. Document showed she was swearing on the phone. So the clinicians had negative opinions of her. Patient perceived some clinicians attitudes as disrespectful, lacking communication skills and did not want to trust them.

		Environmental issues were not raised by the patient but the staff had mentioned that she wanted home modifications and OT had refused them. This issue was not recorded in OT notes or discussed in meetings. Economic situation was not discussed by the patient, professional or the any others in the team in meetings or in the notes. Leisure was not discussed by anyone involved or documented in the notes.	without support but went because staff were busy. Staff said that patients were sometimes not motivated to do things for themselves. Patient's decisional autonomy was frowned upon as she walked to the toilet when she was not supposed to go on her own. Staff said care plans were never forced on the patient potentially giving them decisional autonomy (but not in P3's case). Active participation in goal-setting was not perceived by patient. She was also reluctant as she did not trust everyone on the ward and felt that she did not want to be an awkward patient. Nurse stated that they took consent	Patient did not perceive that goals were discussed with her. Patient agreed goals were blank and patient expectations were also left blank.

			for care plans and negotiated with them which did not happen in this case. Patient agreed goals were blank in the notes. Patient was not an expert in this case as she was afraid of being called awkward did not discuss issues. Further she was not asked for views. Staff said they get patient to fill in document to get information about patient which did not happen in this case. There was no respect for patient autonomy (reported walking to toilet on own). Patient goals were not for independence (perhaps she was already at a high level of independence). Staff said information about ward routines was given to	

			facilitate autonomy. But patient reported not knowing routines. Habilitation was not evidenced in this case. There were steps for empowerment in community as OT record showed follow up by ICT to improve confidence in community mobility. But staff reported that patient wanted home adaptations and this request was refused by OT.	
Partial congruence	The patient's biography included her family responsibilities, carer job and household responsibilities. She talked about this in casual conversations too. Nurse reported that they would get to know the patient by asking them to fill in 'all	Patient felt that there should be a communication channel which extended to the community. Staff also considered safety and prevention after discharge and normally liaised with social services for care after discharge (though not in this case). OT and PT	Informational control in this case was an issue for the patient and staff. Patient was upset on day of discharge for getting inappropriate information. Staff was concerned about volunteering information in case they mis-quote the information given. Patient took the opportunity	Dr reassured her to give her positive hope during ward rounds.

	about me' document. However this was not found in the patient's notes. The records show her social status, her family history of stroke and non-compliance with medications. Emotional issues such as fear, low confidence were stated by patient. OT notes record anxiety but no plans for intervening. Staff did not pick on these issues or discuss them in the meetings. Patient set goals that were personally relevant which included caring, driving and household work. She was not consulted on her goals. She set her own goals as she was not totally inclined to work with the professionals. Staff said patients goals were	records showed follow up in the community. Social activities such as helping others, was mentioned by patient but not by the staff. However during the meeting professionals discussed her going back to caring and family responsibilities. Her social status had also been recorded in OT notes with no plans relevant to it. Patient discussed issues related to health promotion such as fitness and continuing medications. Staff was not specific about these aspects but he said he would aim for prevention of problems following discharge. Compliance with medication was discussed during the MDT meeting.	of the ward rounds to get some information from the medical professional. There was no record of information given to patient in the notes. Informational flow occurred between professionals. Patient wanted information on ward routines which staff said had been given. Patient clarified health issues with doctors during ward rounds. Limited personnel in the rounds also limited information flow between parties.	

	to go back to nursing work and get home adaptations which were refused by the OT. In the meeting staff discussed her goals as wanting to go back to her carer job and family responsibilities.	Notes also had record of non-compliance with medication. Patient mentioned that family helped her cope. Staff also thought about family involvement for collecting information and help with care. However he felt that family involvement can be a challenge if they were blaming. The discussions or notes did not show any family involvement.		

Appendix 4.11 Spread of cases across the continuum of different levels of congruence- Study one

Dimension: Ensuring all aspects of their health problems are attended to (Holistic)	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant
Biological	1234567			
Psychological		24567	13	
Social factors	46	357	12	
Participation		12567	34	
Environmental		6	12345	7
Economic			25	13467
Health promotion		2367	1	45
Carer/family	1	3567	24	
Transition	2	134567		
leisure		57	1246	3

Dimension: Establishing a therapeutic relationship	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant
Clinicians' attitudes		145	2367	
Maintain positive hope	7	1235	46	
Bonding	5	241	367	
Professional respect	7	164	235	
Congruence		14567	23	

Dimension: Identifying and catering to a patient's individual needs (Individualistic)	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant
Biography	467	1235		
Subjective		25	13467	

experience				
Understanding the psychological world	7		123456	
Emotions		23467	15	
Context and time sensitivity	1237	4	56	
Personal relevance		12347	56	

Empowering and sharing responsibility	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant
Active problem solving		15	23467	
Self-efficacy			1234567	
Informational control		234567	1	
Executional autonomy		7	12345	6
Decisional autonomy		1467	235	
Active participation	7	12456	3	
Multi directional ongoing information exchange		134567	2	
Patient as expert	7	14	2356	
Patient autonomy	24	567	13	
Strengthening problem solving		156	2347	
Habilitation				1234567

Appendix 4.12 a Factors Influencing Goal-setting - Sample of Clinicians' data from Study one

WHAT FACTORS INFLUENCED GOAL-SETTING IN THIS SETTING? CLINICIANS' PERSPECTIVES/DATA					
	Prof beliefs attributes and practice.	**Skill/knowledge limitation**	**Experience of Goal-setting**	**System factors**	**Patient attributes**
FG	L: Acute nature not suitable for progressive GS T: Changing status of patients SN: medical orientation to practice	T: Not sure of outcomes/ Unpredictable recovery L/T: Inability to predict recovery M: not used strategy for PCGS N: not sure of recovery C: Goal-Difficult concept to explain N: lack of clarity of information about goal-setting and review SN: not equipped to support psychologically F: not want to predict future		SN: focus is on medical stability L: Increased no of pts. Drs. raise expectation N: GAS- time consuming SN/T: time/ workload SN: staff shortage M: Not based on ward/ workload T: not having continuity of care with same professional C: Information gap for patients/ knowledge of processes N: Invisibility of documents/ ward layout/ Privacy SN/F: poor psychological support for patient SN: Communication within MDT/shorter stay	T/L: Patients set unrealistic goals/ speech problems M: not having families around during working hours L: ambiguous goals/ wanting pre-stroke status. SN/ L: demanding families L: over expectation from patients/ C: unable to specify goals/ difficult to set goals/ Medical instability N: Limited knowledge of recovery T: No prior experience/ SN: Comparing therapy/ Lack of awareness of condition/ setbacks/ unrealistic expectation of patient and family

				F: resources at discharge N: longer time with fly involvement T: Discussions excluding family	F: Cognition Mental capacity Stubbornness/ Reluctance to talk to professionals/ apprehension/ too early for some patients./ confidentiality
PC1	Patient information was from medical notes, team Got an understanding of patient's understanding. Assessment of perceptual, cognitive, family situation, job, risk, pre-stroke status, Worried about patient complaints	Unsure of prognosis Scope of practice	Perceived goals to be to return to work and driving. Goals depended on recovery related to age, co-morbidities, functional level, rehabilitation prospects. Stepwise (building on short term) Goal-setting through MDT , joint assessment, Staff discussed goals with patient and long term follow up on these goals. Difference in perception of goal between patient and professional.	Early discharge, acute setting No time to get to know that person. Environmental/ resource- ward layout not conducive Workload , paperwork (duplication/ overlap) Uncertainty of discharge Staff shortage Multitasking	Patient perceived as honest, keen , motivated, forthcoming, coping skills, Denial, reluctance to get involved, age difference between them, interpersonal skills, communication problems, not being realistic, setting vague goals,

Appendix 4.12 b Factors Influencing Goal-setting Sample of Patients' data from Study one

WHAT FACTORS INFLUENCED GOAL-SETTING IN THIS SETTING? PATIENT-PERSPECTIVES					
	Patient beliefs/status and attributes (character)	**Skill/knowledge limitation**	**Experience of Goal-setting**	**System factors**	**Staff attributes**
FG1	C: felt she had received good attention Cath: Felt like fraud and felt stupid since she presented as a stroke but had no clear diagnosis D: care was better focussed on him compared to previous healthcare experience. D: Has a dislike for hospitals and some health professionals based on a previous experience. Cath: belief that professionals can be, unprofessional, prejudiced and mocking from	Cath: limited information for self, family and friends Cath: Lack of clarity of information/ mixed messages C: Not knowing prevention if current episode was a warning D: Not getting honest answers (open communication) D: GS as an opportunity to clarify ability C: Preoccupied with prior information	C: Information given when asked Cath: Asked questions by professionals, but, they did not explain the situation. D: Unaware of rehab goals C: Unaware of rehab goals. PT explored her goal which was to walk C: Preferred involvement in GS Cath: Mandatory involvement D: not asked about his goals Cath: Patient told to use zimmer for safety C: Goals discussed with patient who expressed desire to walk to toilet and go home. Cath: Does not have a care plan C: Does not have a care plan	Cath: Time limitation C: Staff shortage Cath: difficult to operationalise D: limited explanation of aim of assessment	Prof not sure of information Cath: Talking above patients/ appearing to be rushed C: Unapproachable Cath: Complicated language

	previous experience D: Question staff during ward rounds/ fear /not knowing who to ask C: Feeling inadequate/ stupid		D: Wife acts as communication channel C: Relied on family for communication; may not be appropriate for all due to problems in family		
PC7	Awareness of physical disability leading to unhappiness. Realisation of stroke from others' sympathy Satisfied with care Belief in health care Contentment Self-efficacy belief was based on Pre-stroke lifestyle Trusts and relies on professionals and husband	Contemplated whether personality trait was risk for stroke	Involvement in GS by physio Compliant with goals set by professionals Confusion regarding discharge destination. Husband found a place for patient in a preferred rehabilitation setting	Focus of discussion was on investigation, referral and discharge plan.	Considered patient knowledge Suspected patient was confused. Record that patient did not want W as discharge destination was overlooked by staff.

Appendix 4.12 c Principles and Strategies to make Goal-setting more Patient-centred-Sample data from Study one

What are the principles and strategies to make goal-setting more patient-centred?				
	Principles (patients)	Strategies (patients)	Principles (staff)	Strategies (staff)
PC3	Need for reassurance Need for guidance Need for developing trust in relationship Understand individual differences Develop communication skills in professionals	Need to know processes in hospital friendly/ sense of humour Communication channel post discharge Teach them and show them how to get involved in process	Individualistic approach Motivate (stress on importance of goals) To have guidance on PCGS	Ward introduction Information on team roles/responsibilities. Awareness of the processes in rehabilitation Involving family (clarity about who gives them information) Work book to get to know patient's preferences Asking specific questions(info from patients) using simple terms leading to goals Explore patient's pre-stroke lifestyle and link to goals Involving patient in deciding carer input Involving different professionals/ collaborative assessment and goal-setting Negotiating goals Follow up information delivered during ward rounds
PC4	Acknowledging differences in people Involvement in care if appropriate and needed Need for guidance	Professional taking the lead by initiating discussion	Individualistic approach Involving patient in goal-setting	Exploring patient preferences/ needs Explore pat pre-stroke status Guiding with goals Joint assessment with

				professionals Explaining purpose of therapy Documenting patient goals Discussing these documented goals in MDT Patient's pre-stroke status and discharge plans discussed during ward rounds
PC5	Involvement in goal-setting if needed	Feedback on progress and motivate based on recovery Discussion during routine rounds	Holistic approach/ Consider bigger picture Individualistic assessment Medical stability a requisite Giving patient a voice. Pt Involvement in GS Involving family/ Considering family's wishes	Monitoring progress of goals Reflecting on strategies to achieve goals Exploring patient needs/priorities Explore pat pre-stroke status Use of patient centred outcomes Adopting ICF model- identifying participatory needs and quality of life issues. Scheduling of therapy Specific personnel on ward for continuity of care. Collaborative GS with other professionals Patient involvement with MDT Exploring issues with an open tool/ build goals on that. Reassurance about recovery was given during ward rounds

Appendix 4.13 Sample illustration of the logical derivation of key themes and subthemes- Study one –Theme 1- Subtheme 2

Patient disempowerment due to deficits in communication

Appendix 4.14 Generic features of the documents analysed in Study one

	Name of the document	Authorship	Structure and Content	Relevance to goal-setting	Frequency of use	Position of document
1.	Physiotherapy Neurological Assessment	Physiotherapy staff	Body chart for tone and sensation, level of consciousness, swallowing, communication, respiratory status, continence, sensation, proprioception, pain, continence, patient expectations, movement analysis and function (Head /Neck /Trunk /Limbs), lying, sitting, standing- posture, balance, transfers, gait, clinical analysis and reasoning for deficits.	Opportunity to record patient expectations	Once-close to admission	End of the case notes in a section for physiotherapy notes
2.	Physiotherapy treatment document	Physiotherapy staff and students	Physiotherapy treatments, date, indicators and outcome measures The treatments are listed in the first column and a tick against each date in the subsequent columns.	There is a statement that states "this treatment plan has been fully discussed and agreed with the patient. This includes options for treatment and amendments	There is a tick for every day except the weekend indicating therapy everyday	This is placed at the end of the notes after the Blue sheet (care programme record)

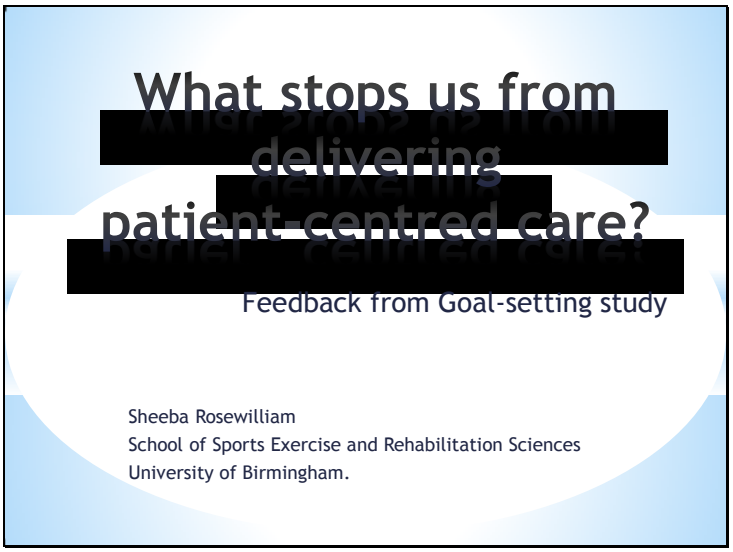
				to the plan and options for non-treatment" There is a tick for this statement for every day of treatment.		
3.	PT care programme record	Physiotherapy staff, assistants and students	In blue colour. Has three columns: Impairment, activity and participation Working status of patient, occupation of patient, return to work plan requirement (yes or no) Overall aim: a tick box with resolve, maximise potential, maintain or sustain, prevent, provide a diagnostic consult and educate. Is there a need to involve other members of MDT- Yes or no question (Note who in treatment) Anticipated length of treatment number of sessions and over how many weeks.	A table for Goals agreed with patient and physiotherapy goals Date, short term and long term goals and predicted dates for achievement of both goals.		
4.	Physiotherapy record	Physiotherapy staff and students	Dated and plain sheets to record notes in SOAP format (Subjective, Objective, Analysis and Plan).	Records long term and short term goals under plans	Every patient contact is recorded which is most often	In a section for physiotherapy notes after the Physiotherapy

				and reviews of these goals.	once every day.	neurological assessment
5.	Occupational Therapy Neuro screening assessment	Occupational therapists	Considers motor, sensory, perceptual, cognitive, behavioural social, pre stroke status and environmental factors.	Recommendations refer to their goals or plan of action.	Once-close to admission	Towards the end of the case notes.
6.	OT neuro assessment	Occupational therapists	Considers history, capacity of Person (affect, cognition, Physical, spirituality) and Social environment (social, institutional) Attached with this is a tick box document with Physical environment about home, Self- care (Personal, functional, community management) Productivity (household chores, making drinks, food, return to paid employment, voluntary work, Leisure hobbies, Interests).	Records intended for holistic assessment of patient needs. Therapists record patient views about goals in some parts.	Once-close to admission	Kept after Physiotherapy documents.
7.	Occupational therapy assessment	Occupational therapists	Table with highlights in bright green. Contains treatment plan, Treatment aims, Therapist plan, Consent to communicate with relatives and carers and date completed	Goals agreed with the patient, and outcomes	Once-close to admission	After the OT neuro assessment
8.	Continuation sheets	All therapists, nurses, doctors and	Interactions with patient and other professionals are recorded.	Plans are written by different professionals	Every contact on every day is recorded.	Middle of the case notes after the admission documents.

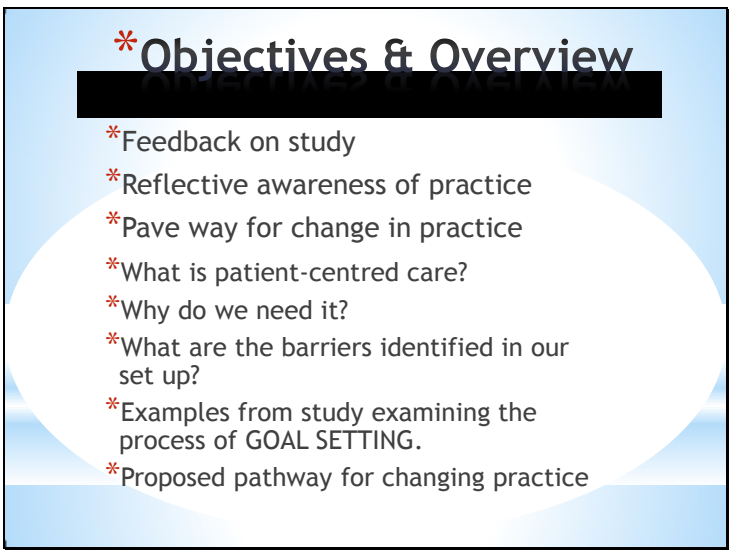
		other professionals who come into contact with the patients.		who include goals for patient's rehabilitation or their own plan of actions.		
9.	MDT weekly sheet	Consultant or SPR or Stroke co-ordinator write on this in the presence of the rest of the team.	Patient's diagnosis, details of functional independence, mood, social/domestic situation and referrals. There is single row in the table for each profession to record their viewpoint.	Finally there is a section for MDT agreed goals and discharge destination along with estimated date.	Done weekly on Mondays	Placed after the continuation sheets towards the end of the notes.
10.	Transfer document	Staff nurse on duty	Has patient details; problems; MH; Mental status; Infection status; medications; concerns/monitoring; diet &drink; Water low score/mattress	Rehabilitation goals box	Once at discharge	This is the first document in the Sub acute notes

Appendix 5.1 Feedback from first study

Slide 1



Slide 2



Slide 3

*The concept

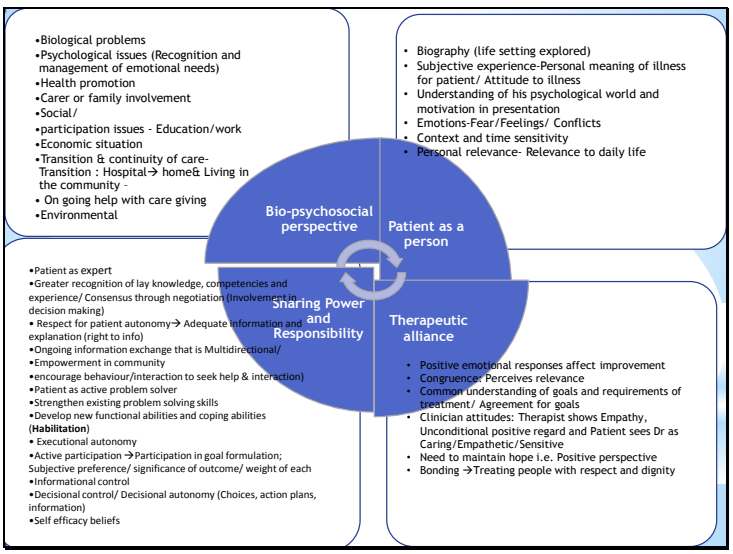
*Hard to pin down, define, interpret and measure.

*Stroke specific definition of PCC states that PCC

- ❖identifies communication skills,
- ❖uses effective strategies,
- ❖identifies outcomes valued by patient and the quality of participation,
- ❖monitors and measures at appropriate points in rehabilitation and
- ❖uses information to help decision making.

(Lawrence and Kinn, 2011)

Slide 4



Slide 5

* Why must we be patient-centred?

*Reason for choosing caring profession

*responsibility to the patient by involving them more

*might have better outcomes.

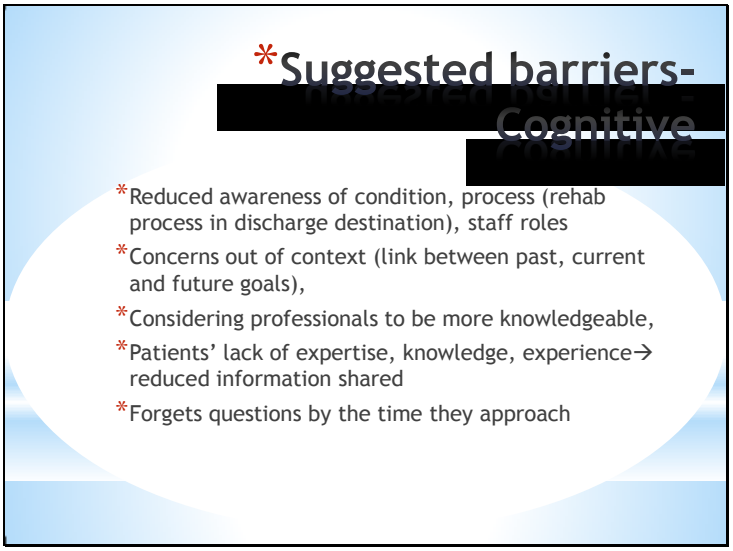
*Patients know where they are going, they can monitor themselves.

*Joint professional goals can be set.

*Patient led goals can be formulated.

*Guideline & Policy requirement (RCP 2012)

Slide 6



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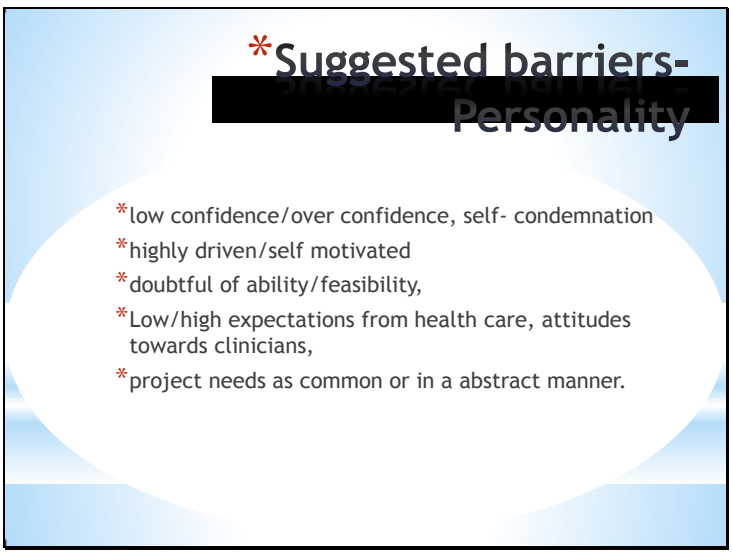

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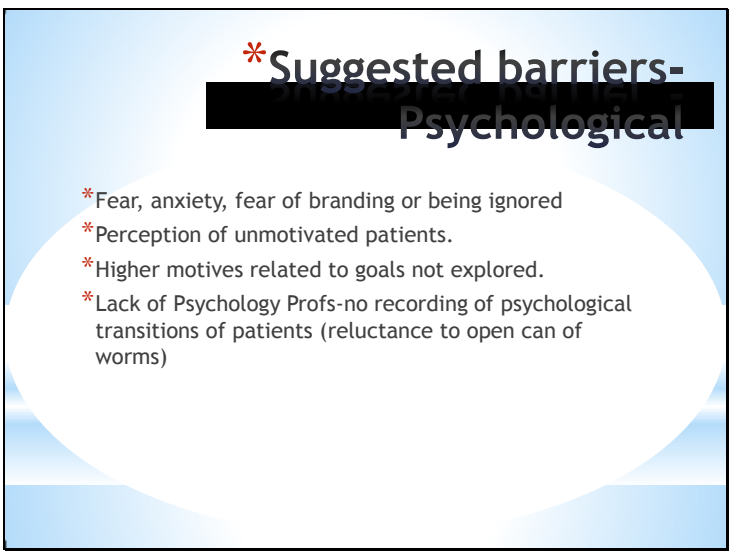

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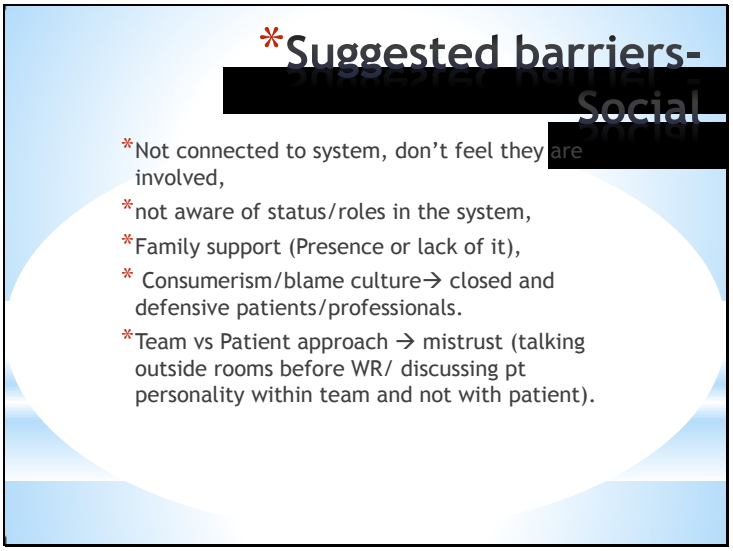

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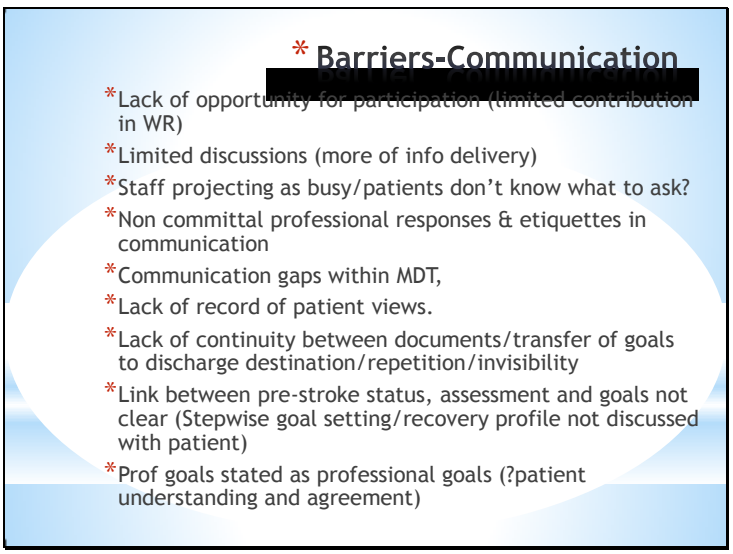

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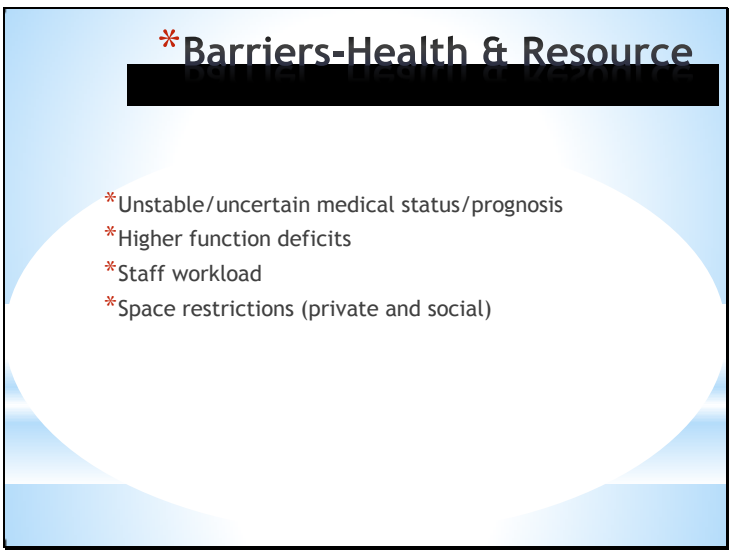
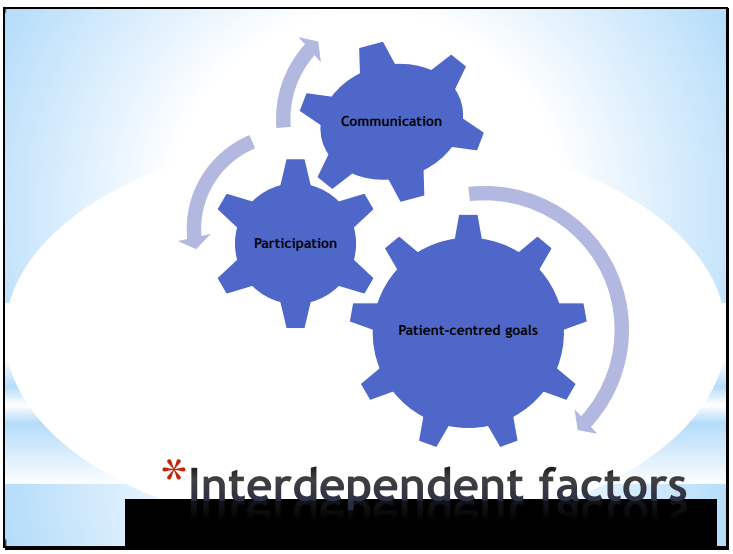


Slide 12

*Barriers-Practice

- *Staff knowledge
- *Bureaucracy → run of the mill work/day to day care
- *lack of professional autonomy → devolve to other professionals,
- *break down of communications/interprofessional dilemmas, not want to predict future.
- *short/limited WR & medication and discharge focussed MDT meetings,
- *Limited contact with families or families seen as obtrusive(no strategy to link with family)
- *reduced LOS not conducive → routine quick fixes(conveyor belt approach)
- *priorities different in acute care for patient and professional (physical/emotional, leisure/occupation, spiritual/cultural)
- *risk avoidance/admin/mixed responsibilities deviate focus.

Slide 13



*Interdependent factors

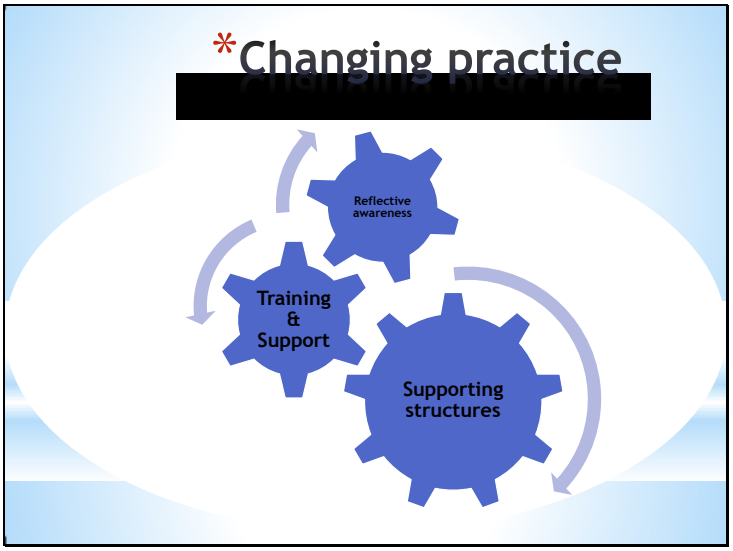
Slide 14

* Can we achieve patient-centred practice?

- *Cognitive
- *Personality
- *Psychological
- *Social
- *Health
- *Resource
- *Communication
- *Practice

- *Bio-psychosocial perspective
- *Patient as a person
- *Sharing Power and Responsibility
- *Therapeutic alliance

Slide 15



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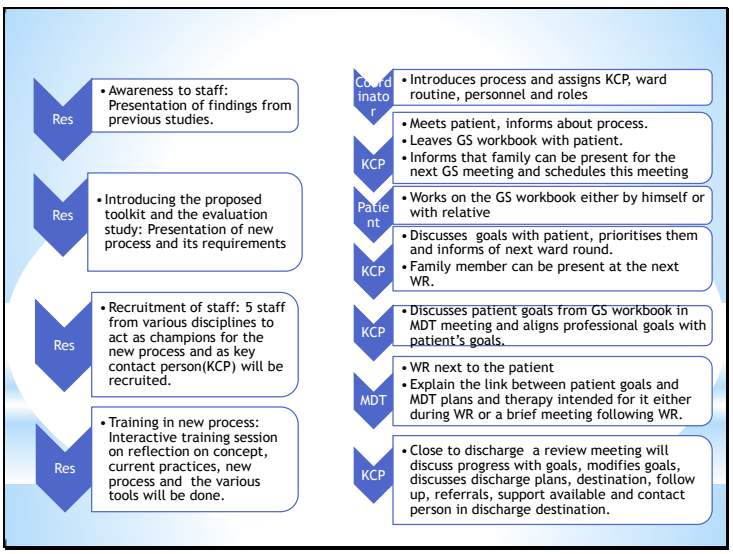


Slide 17

Appendix 5.2 Logical flow of the identification of challenges and overarching strategies from the study findings and the literature

Table showing Logical flow of the identification of challenges and overarching strategies from the study findings and the literature						
Aspects	**Limitations identified**	**Challenges summarised from findings**	**Potential strategies identified from study**	**Tools proposed in study**	**Strategies and tools suggested in literature**	**Overarching strategies**
Patient's biography	Leisure and spirituality not recorded despite the allocated space in the records. Socialising mentioned by patients was not identified by professionals. The above limitations were probably due to 'tunnel vision' to identify patient needs through profession specific assessments.	Set ways of working and lack of flexibility or probing of patient needs. Limited by contextual factors.	Patients suggested exploring their pre-stroke status and use that as reference point for goals and a need to explore cultural and spiritual beliefs. Professionals preferred a structure e.g. questionnaire to help understand individualistic aspects. Need for an informal structure to discuss hobbies and socialising.	Holistic assessments. Exploring premorbid status to understand patient holistically. Structured workbook with open ended questions. One-one meetings for informal discussions.	Goal menu which included exploration of functional, medical, psychosocial aspects and standardised tools (Glazier *et al.*, 2004). COPM and life goals questionnaire were considered as holistic goal setting measures that improved patient participation	Altered ways of working. Structural support. Communication channel.

					(Playford *et al.*, 2000; Leach *et al.*, 2010).	
Carer and family involvement	This was considered necessary by patient but clinicians thought it challenging due to acute practice.	Professionals limited by contextual factors. They had set ways of working.	Getting information from wife to decide goals, family involvement based on patient's choice.	Options for family to get involved based on patient's choice	Encouragement of family and others was shown to enable patient involvement (Brown *et al*., 2014). However families could redirect the patient goals to suit their agenda (Levack *et al.*, 2009).	Communication channel. Alternate ways of working.
Health promotion	Patients were keen for information on health promotion. No record of what information or pamphlets were given.	Set ways of working within professionals roles.	Professionals delegated this aspect to volunteers from stroke association.	Exploration of health promotional needs and information, support and referral as required in the one-one meeting.		Structural support with cues Communication channel
Informational	This was limited by	Set ways of working	Ward rounds gave	Ward rounds as	Information	Building

control and Ongoing multi-directional information exchange	brief ward rounds, medical orientation and limited staff participation. Professional issues prevented flow of information to patients (hierarchy) Information was overlooked in notes resulting in mis-communication. Goals did not cascade to professionals in the team. Patients' lack of awareness of facilities, routines, roles, processes and their condition and goals. Limited listening, use of jargons and lack of communication channel were seen.	within professional roles Contextual factors of hierarchy and bureaucracy Communication gaps	opportunity to patients to gain information. Doctors reassured, informed about discharge and follow up during ward rounds. Families acted as communication channels. Patients wanted information access from approachable staff. Open channel using simple language was suggested by patients. They wanted information on the roles of professionals, their role, routines on the ward and the process of goal-setting Collaborative goal-setting and Goals review during MDT meetings. Feedback to patient	an opportunity to discuss patient's goals and give feedback from MDT meeting. Family invited to attend war rounds as MDT with family is not feasible in this acute setting. Information (booklets) about goal-setting process to orient them to the process. Other information given as need arises. Documentation of patients' views. Patient's goals discussed in MDT meeting.	provided by professionals was found to enable patients' involvement in goal-setting (Holliday *et al* 2007). Introductory pamphlets were recommended for this purpose (Elsworth *et al.*, 1999). Introducing professional roles, the rehabilitation process and realistic goal-setting was suggested to improve patient engagement with the process (Levack *et al.*, 2011).	on existing practice Awarene ss of challeng es and process. Commun ication channels Alternate ways of working Cues within structural support

			from MDT. Contact for informational support.	Feedback to patient in one-one meeting. Keyworker role.	Listening skills, ability to think laterally and provide guidance were suggested as essential for professionals during goal-setting (Hale and Piggot, 2005)	
Decisional autonomy	Professional plans overruled patient's choices. Patients left decision making to professionals. Professionals perceived goals were discussed in MDT meetings and therapy sessions.	Professional dominance Patients' subservient behaviour	Consenting procedure and consultant's discussion during ward rounds. Help patients' graded decision making by giving them time to absorb, digest and then opportunity to ask questions. Professionals suggested informing patients about process, asking for goals, negotiating	Informing, shared goal-setting in steps with time gap between steps. Information on goal-setting. Space to document patient goals.	Documentation of patient goals was recommended by therapists in Northen *et al* (1995).	Awarene ss of practice. Alternate ways of working.

			goals, guiding or signposting for setting goals and reviewing goals. Documenting patient goals was also suggested.			
Autonomy	Goals for independence were set but patients were not aware of treatment plans to achieve these goals.	Communication gaps	Consider long term goals. Explain link between therapy and goals	Record patient's broad life goals Explain link to life goals and therapy.		Awareness of process Alternate ways of working Structural support for plugging communication gaps.
Executional autonomy			Some patients delegated responsibilities to family or friends to meet their needs. Professionals	Key worker to be the patient advocate	Motivated therapists had acted as mediators between the team and the	Structural support

			suggested giving the patients a voice in the process.		patient to set goals collaboratively (Lloyd, Roberts and Freeman, 2014)	
'Psychological world' and 'Subjective experience of illness' 'Emotions'	Often the patient's motives were not identified. Professionals described behaviours without understanding motives behind these behaviours. Experiences influenced patients' beliefs and needed to be explored. Some emotions were recorded but not monitored or have goals for intervention. If there was an intervention it was not based on patient's need.	Set ways of working and lack of flexibility or probing of patient needs. Limited by beliefs.	Understanding subjective experience helped to understand the inner motives of patients. Vicarious experiences helped to realise potential and cope. Psychological support including hope, reassurance, confidence and encouragement to participate were requested by patients.	One-one contact to get to know patient. Encouragement to involve in goal-setting.		Awareness of beliefs and practice. Communication channel Motivational channel

Environment	Not explored since patients moved on to further rehabilitation. Patients could not identify environmental needs from the hospital.	Set ways of working. Limited due to contextual factors.				Awareness of practice.
Patient as an expert	Patients did not see themselves as experts sometimes. Patients had mis-conceptions about goals (goals were for younger people, goals were clinicians' responsibility and collaborating with clinicians restricted them). Professionals also felt that patients lacked experience, knowledge and insight. Their condition, severity and co-morbidities were suggested by	Patient beliefs (subservient) Professional dominance Contextual limitations	Need to record thoughts/ queries Inform about processes, ward routines. Graded information provision and time to absorb information was suggested.	Opportunity to record informational needs and raise these with professionals. Information shared based on the identified need of the patient.		Awareness/ reflection on beliefs and behaviour. Structural support with cues.

	professionals to limit participation.					
Active problem-solving and Strengthening problem solving skills	Professionals did not identify patient's ability to put forward problems, prioritise and seek solutions.	Set ways of working	Sometimes patient's understanding of problems was explored, patient identified problem was assessed further, problems were broken down and possible causes and solutions explained. Patients' insight improved with time and trying out activities. Patients suggested asking specific questions. They wanted encouragement with problem solving, linking goals to therapy and document strategies to achieve goals.	Opportunity to prepare for goal-setting. Workbook to consider goals prior to meeting to prepare for goal-setting. Open ended questions in the workbook		Structural support with specific questions. Motivational channel. Awareness/ Training to set collaborative goals.
Self-efficacy beliefs	Professionals did not encourage this aspect	Patient beliefs and set ways of working.	Families encouraged confidence in patients.		Encouragement	Awarene

			Patients based it on their recovery and life-style prior to stroke. Doctors discussed recovery during ward rounds with patients.		of family and others was shown to enable patient involvement (Brown *et al*., 2014). Patient's self - determination and beliefs about recovery were seen to influence patient involvement in goal-setting (Brown *et al*., 2014; Holliday *et al*., 2007)	ss Alternate ways of working within existing practice. Structura l support.
Active participation	Patients did not recollect participation or their goals. Patient agreed goals were blank	Set ways of working	Wanted involvement but also participation left to their choice. Flexible participation was suggested by patients. Encourage involvement in process.	Workbook to understand patient better and to explore patient goals	Presence of patients in these meetings, goals documented in front of the patient, a copy of goals given to the patient and updating the	Structura l support with cues Motivati onal channel Alternate ways of

					progress in goals were also suggested by the patients to facilitate patient-centred goal-setting (Young, Manmathan and Ward, 2008)	working within system
'Clinician's attitudes', 'professional respect', 'maintaining positive hope' and 'bonding'	Poor communication from professionals was perceived as disrespect. Professionals were reluctant to give hope or reassurance which patients were keen on. Negative opinions about each other perceived by patients and professionals did not help bonding.	Communication gaps Working within scope Professional and patient beliefs causing reduced rapport.	Friendly approach, asking them for their opinions helped to bond in some situations. Patients wanted hope, reassurance, confidence and feedback. One to one contact to understand patient was suggested. Patients also suggested a contact person to get to know them, care and share information with them.	Keyworker role		Awareness of beliefs, behaviour and consequences Motivational channel Communication channel via personalised

			Raising awareness amongst professionals about their communication and behaviour.			contact.
Transition to community	Professionals did not see beyond acute care Plans were conveyed rather than being discussed Patient left with concerns about continuity of care	Professionals' set beliefs and working within scope	Discussion of care continuum with patient and communication channel post-discharge was suggested. Information about discharge			Awareness of behaviour and consequences. Structural support with cues
Organisational	Bureaucracy Confidentiality, referral by seniors and focus on reducing complaints. Hierarchy Patients' non-involvement in team processes such as meetings and goal-setting. Workload	Contextual limitations	Collaborative/ skimmed documentation Visibility of documentation Joint assessments Documentation discussed in the MDT meeting.	Modified documentation for setting goals. Using documentation for MDT discussion.		Awareness of practice Structural support and alternate ways of working.

	Paperwork Multiple roles					
Professionals' Knowledge and skills	Felt inadequately trained in process, methods and theory Professionals' lack of social skills. Perceptual gap about their current practice of asking for goals during therapy and discussion in MDT meetings. There were no records and patients were not aware of their goals.	Professional beliefs about their expertise.	Guidance, training and support to carry out patient-centred goal-setting. Inter-professional collaboration and understanding of roles.	Training professionals to improve awareness of current practice, improved patient-centredness and theory of goal-setting. Documents and training to involve different professional groups.	Professionals had	Awarene ss, training and support. Alternate ways of working.
Resources	Lack of private space for discussion and inadequate therapy resources to assess needs	Contextual				Alternate ways of working.

Brown, M., Levack, W., McPherson, K. M., Dean, S. G., Reed, K., Weatherall, M. & Taylor, W. J. (2014). 'Survival, momentum, and things that make me 'me': patients' perceptions of goal setting after stroke'. *Disability and Rehabilitation,* 36**,** 1020-1026.

Elsworth, J. D., Marks, J. A., McGrath, J. R. & Wade, D. T. (1999). 'An audit of goal planning in rehabilitation'. *Topics in Stroke Rehabilitation,* 6**,** 51-61.

Glazier, S. R., Schuman, J., Keltz, E., Vally, A. & Glazier, R. H. (2004). 'Taking the Next Steps in Goal Ascertainment: A Prospective Study of Patient, Team, and Family Perspectives Using a Comprehensive Standardized Menu in a Geriatric Assessment and Treatment Unit'. *Journal of the American Geriatrics Society,* 52**,** 284-289.

Hale, L. A. & Piggot, J. (2005). 'Exploring the content of physiotherapeutic home-based stroke rehabilitation in New Zealand'. *Archives of Physical Medicine and Rehabilitation,* 86**,** 1933-1940.

Holliday, R. C., Cano, S., Freeman, J. A. & Playford, E. D. (2007). 'Should patients participate in clinical decision making? An optimised balance block design controlled study of goal setting in a rehabilitation unit'. *Journal of Neurology, Neurosurgery, and Psychiatry,* 78**,** 576-580.

Leach, E., Cornwell, P., Fleming, J. & Haines, T. (2010). 'Patient centered goal-setting in a subacute rehabilitation setting'. *Disability & Rehabilitation,* 32**,** 159-172.

Levack, W. M., Dean, S. G., Siegert, R. J. & McPherson, K. M. (2011). 'Navigating patient-centered goal setting in inpatient stroke rehabilitation: how clinicians control the process to meet perceived professional responsibilities'. *Patient Education and Counseling,* 85**,** 206-13.

Levack, W. M., Siegert, R. J., Dean, S. G. & McPherson, K. M. (2009). 'Goal planning for adults with acquired brain injury: how clinicians talk about involving family'. *Brain Injury,* 23**,** 192-202.

Lloyd, A., Roberts, A. R. & Freeman, J. A. (2014). "Finding a Balance' in Involving Patients in Goal Setting Early After Stroke: A Physiotherapy Perspective'. *Physiotherapy Research International,* 19**,** 147-157.

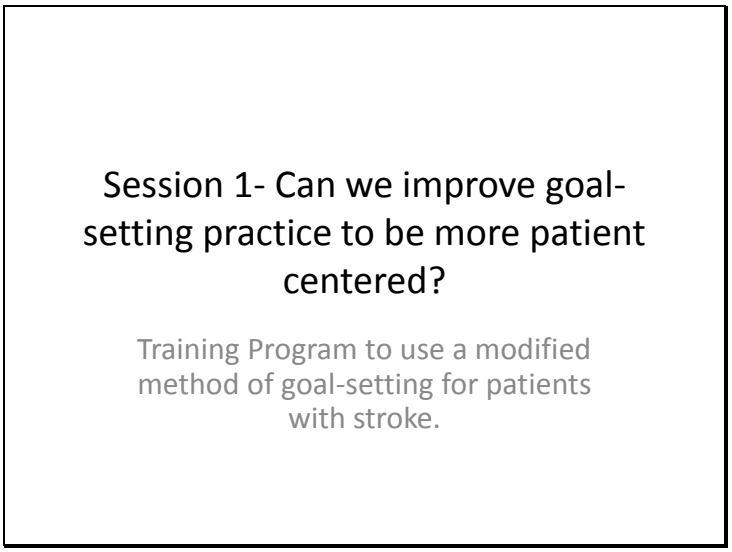
Northen, J. G., Rust, D. M., Nelson, C. E. & Watts, J. H. (1995). 'Involvement of Adult Rehabilitation Patients in Setting Occupational Therapy Goals'. *American Journal of Occupational Therapy,* 49**,** 214-220.

Playford, E. D., Dawson, L., Limbert, V., Smith, M., Ward, C. D. & Wells, R. (2000). 'Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting'. *Clinical Rehabilitation,* 14**,** 491-496.

Young, C. A., Manmathan, G. P. & Ward, J. C. (2008). 'Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff'. *Journal of Rehabilitation Medicine,* 40**,** 190-4.

Appendix 5.3 a Slides for session 1- Can we improve goal-setting practice to be more patient centered?

Slide 1



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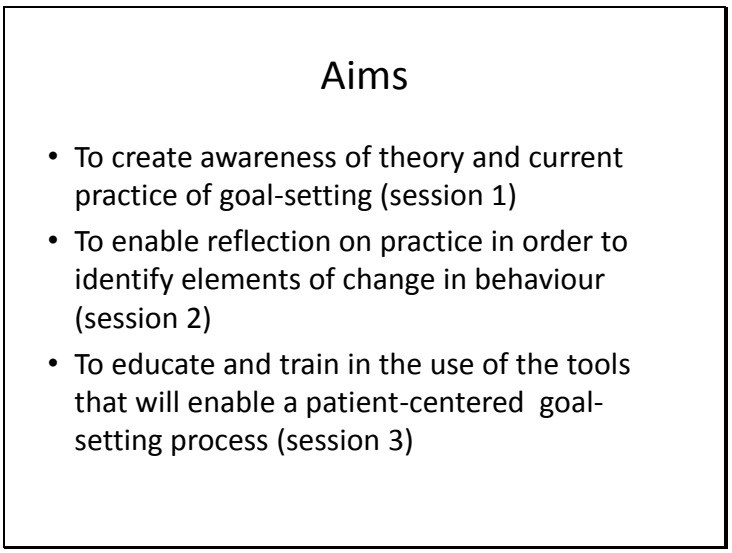
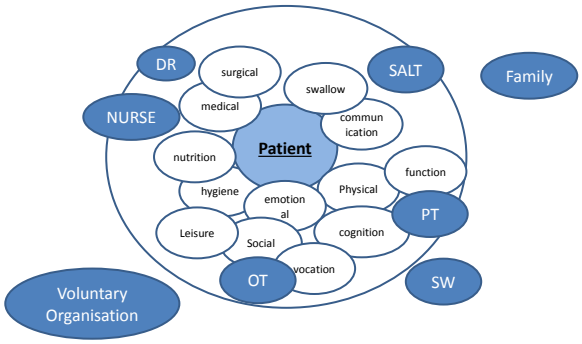


Slide 3

Session 1 -The why and what….



Slide 4

Goal-setting (RCP 2012)

- The setting of goals is central to effective and efficient rehabilitation.
- Goal setting can be defined as the identification of and agreement on a behavioural target which the patient, therapist or team will work towards over a specified period of time.
- Maintain set of patient-centred goals

Slide 5

Evidence

- The setting of goals with the patient, is associated with more behavioural change
- Behavioural change is more likely if goal planning is supported with specific interventions.
- Setting both long-term and short-term goals is more effective than setting only long-term goals.
- Setting goals may improve the long-term effectiveness of interventions (adherence).
- Significant patient involvement in goal setting is important to reduce anxiety and stress.

(Mcgrath and Davies 1999, Wade 1998, Levack et al 2006, Wade 2009)

Slide 6

Patient-centered care

- NSFOP-DoH 2001- Standard 2: Person-centred care
- NSF for LTC- 2005- Quality requirement No.1: A person centred service
- Darzi 2008 -People want a greater degree of control and influence over their health and healthcare-
- DoH 2010 -The system will focus on personalised care that reflects individuals' health and care needs –

Slide 7

Why be patient-centred?

Ozer and Kroll (2002).
Jones et al., (2000).
- Dixon et al., (2007)
- Bandura and Locke (2003)

Slide 8

So what is patient centeredness?

- In the opinion of patients…

"*Patient centredness is an overall philosophy in which patients have an active involvement in managing health care in partnership with service providers who understand and respect their needs*"

- Cott 2004

Slide 9

Case Study -1

Rahman

Please read the following story and identify aspects of patient-centredness in setting goals for him.

Slide 10

What is PC Goal-setting?

Key Aspects:

1. Bio-psychosocial perspectives
2. Patient as a person
3. Sharing power and responsibility
4. Therapeutic alliance

Slide 11

Current practice of goal-setting.

The obscure patient

+ The not-so powerful professional

+ The fragmented process

= Effect of combining the above

Appendix 5.3 b Case study for session 1-ver 2

Rahman

Rahman is a married male of Asian descent (Bangladesh) but has no children of his own. He lives with his wife and works as a managing director of a social work company that provides staffing for care homes. He works as a social worker with the children in care homes who are classed as juvenile delinquents. Prior to his stroke he played cricket and tennis once every week, worked full time in the care homes and ran an amateur drama club.

Rahman describes his characteristics as a person who thinks through twice before doing anything. He perceives that his stroke has slowed down his thinking process, caused weakness in his body affecting his movement and speech problems. He realised the effects of stroke the day after he had it. However he believes that he will recover with time.

Rahman identifies his needs in the hospital as cultural- describing massage as a need. He believes it would help healing based on his reading of the Hindu scriptures. He states that the public especially those at the risk of stroke need awareness of what happens with stroke because they lack the understanding. Then they might take the initiative with the support of professionals to help themselves.

Rahman's motives are his attachment to the children he works with and he has high aspirations for them. He states his goals as wanting to return to his family, to do simple things like shopping and be normal just to be able to eat and drink and be happy. He also states he wants to gain power (potentially control over the situation). Regarding the process of GS he says he wasn't consulted about his care. It was rather decided by the consultant. He states that he was willing to contribute but lists challenges as professionals not wanting to listen, assuming their expertise and hence not seeking patient involvement. He has been asking about his care plan since he came in but has not heard anything about it or whether it was being followed. He has asked professionals and they have said decisions have been delayed due to his status; however he questions how decisions can be made without his involvement. Instead he feels professionals project a negative opinion of his recovery. He said options were not discussed with his wife or himself. He did not want to push too much as he might be considered as a bother as he was already considered a pain in the neck by some staff.

He suggests that professionals should be willing to listen to patients, adopt an humanistic approach to care, record patient views in the care plans. Further the patients should be made aware of their care plans, encourage them to involve in the planning for care, provide information on the care processes and roles of professionals. Above all they should respect the patient's intellectual capacity.

Registrar for Rahman

Doctor reports getting information about patients from the GP referrals or from A&E or the family and carers. This particular patient had a basal ganglia bleed and they had contemplated surgery but not proceeded due to unstable ECG. He has been left with left sided weakness resulting in inability to move. He also seemed to have word finding difficulties resulting in

frustration and low mood. He was previously a smoker. He seems to be improving in the past few days as he is less drowsy.

The goals were based on the management of the pathophysiological consequences. The patients needs have been identified as regulation of BP, cholesterol, advice on smoking and prevention of secondary complications such as pressure sores, contractures and spasticity. Further they needed to improve his sitting balance and moving out of bed. He needed repeat scans if his condition deteriorated. These principles of rehabilitation of early rehabilitation and prevention of secondary complications were the motives for management of this patient.

His long term goal was defined as being able to walk with a stick by the end of three months and needing supervision with washing and dressing. The dr believed that since his pathology would resolve better his recovery potential was better.

The treatment should involve the MDT based on his above needs. It will include monitoring his nutritional needs as he has refused NG tube repeatedly. His hydration has to be monitored. He needs to be positioned. Therefore the SALT will be involved for problems with swallow and dysphasia. Treatment will involve patient education about the support available, information about condition and about voluntary organisations that can help with stroke.

Goals were set for a patient based on their assessment of history of condition, identified cause, risk factors and family history. They would usually be about surgical intervention, preventative medication, reduction of risk factors or referral to specialists. They will consider influence of the pre-stroke status, co-morbidities, patient motivation, social support available and the pathology.Generally the patients' goals are set in the weekly MDT following a discussion of the above factors. They talk about incontinence and complications such as spasticity and contractures in these meetings. Then discharge plans are made taking into consideration the needs, level of support, potential for rehabilitation and need for rehabilitation following goals setting these goals will be conveyed to the patient.

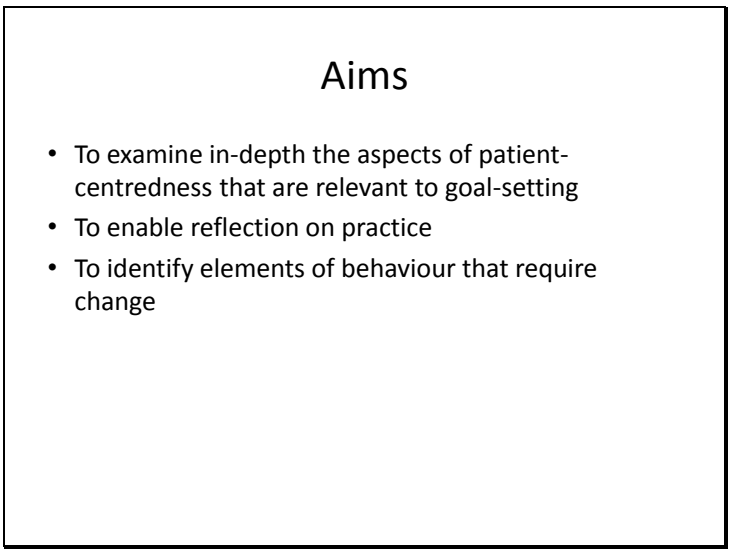
PCGS involved explaining goals to the patient, checking how much information the patient knew, explaining the condition to the patient. The patient has been told that his goals were to maintain his BP, monitor his consciousness level, observe his neurological status, keep him hydrated and nourished. PCGS further meant, for this patient, to adopt a flexible approach for this patient and making several attempts to collaborate with the patient. PCGS meant involving patient, respecting patient wishes and ideas. It involved reassuring patient and giving positive hope. PCGS would build confidence and strength. The patient would be better engaged with the therapy process; therefore he will be motivated and interested. He will have better awareness of plans. There could be faster recovery in both mental and physical problems resulting in reduced morbidity and length of stay. The motive for such an approach would be to help patient as much as possible.

PCC and PCGS can be enhanced by giving more information about team and their roles, the patient's aims and goals of treatment. It would help to follow the guidelines which advocate patient involvement. This should be done with the patient's best interest in mind. Use of best evidence on rehabilitation and prevention of secondary complications is a part of PCC. Listening to patient will involve asking them for their concerns, opinions and expectations. Families can also be involved along with involvement of voluntary organisations.

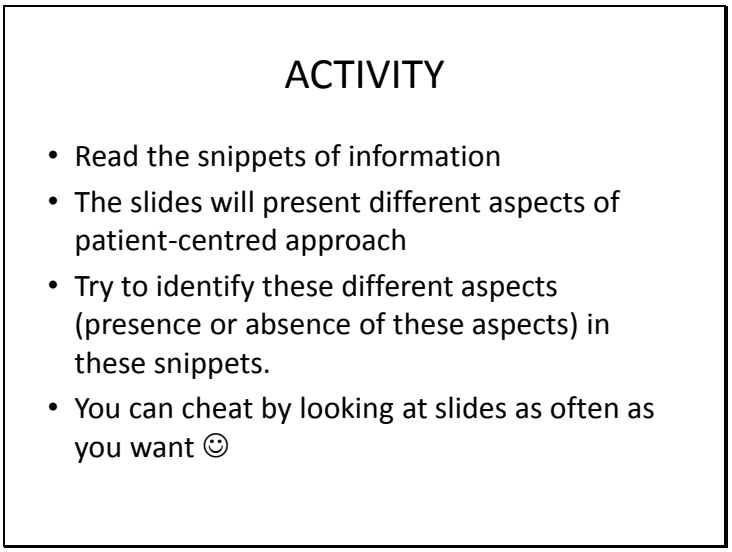
Appendix 5.3 c Slides for session 2-Aspects of patient-centred goal-setting

Slide 1

Slide 2



Slide 3



Slide 4

INDIVIDUALISTIC approach

- Emotions- feelings following stroke
- Understanding of motives- what is their motivation/values in life
- Biography- account of lives
- Subjective experience- experience of illness/hospitalisation both current and previous
- Context and time sensitivity- sensitive to one's life context and in relation to different periods in life such as past or future
- Personal relevance- how relevant the goals , interventions, outcomes are relevant and measured by personally relevant criteria.

Slide 5

BIOPSYCHOSOCIAL approach

- **Biological problems-** medical/physical/ higher functions/ speech and language functions/ nutrition
- **Social factors -** interaction of individual to the group or the society
- **Psychological issues-** mind such as affective or cognitive functions and entails thoughts, emotions and behaviour
- **Participation issues-** functioning of individuals in social situations
- **Health promotion -**enabling people to increase control over their health
- **Carer or family involvement**
- **Environmental-** within the rehabilitation setting and in the community
- **Transition & continuity of care** steps taken during hospitalisation to enable them to independently function at discharge and in the community
- **Leisure**

Slide 6

EMPOWERMENT and SHARING RESPONSIBILITY

- **Active problem solving & Strengthening existing problem solving- -** patient would be able to put forward problems, prioritise them, reason out and seek solutions for the problems, professionals will assist in breaking down the problem
- **Self-efficacy belief -** patient perceives that he is capable of achieving positive outcomes
- **Control over information-** ability of the patient to get required information
- **Autonomy & Respect for patient's autonomy-** ability of the patient to carry out his decisions or delegate actions ; respecting their need for independence and therefore providing opportunities in the form of information
- **Active participation in process**
- **Ongoing multi-directional information exchange -** flow of information between various parties
- **Patient as an expert-** professional acknowledges lay knowledge, experience, and expertise
- **Empowerment for community living-** help with care in the community.

Slide 7

Identify aspects of relationship breakdown in this clip

- http://www.pilgrim.myzen.co.uk/patientvoices/flv/0072pv384.htm

Slide 8

THERAPEUTIC RELATIONSHIP

- **Clinician attitudes** of caring, empathy, sensitive as perceived by patient and clinician showing positive regard for the patient.
- **Professional respect for** - patient's right to moral respect, participation in a democratic process
- **Maintaining positive hope** - need for the professional to help patient maintain the positive perspective in all situations.
- **Bonding** is the establishment of a personal bond between the patient and professional where they treat each other with respect and dignity.
- **Congruence** common understanding/agreement of goals

Slide 9

To finish…

- Think of one thing you would change in your goal-setting practice related to the following aspects

Therapeutic relationship

Empowerment & Sharing responsibility

Bio-psychosocial approach

Individualistic approach

Appendix 5.3 d Worksheet for creating awareness about dimensions of patient-centredness

Worksheet 1- Aspects of INDIVIDUALISTIC approach

Please read the snippets of information given. Given below are aspects of care that are relevant to an INDIVIDUALISTIC approach to goal-setting. Now try to identify these aspects in the information given in snippets. You will be looking for these aspects in your interactions with your patient to understand the patient better and set goals relevant to these aspects.

Peter is software professional working with the BT. He was keen on DIY, played the guitar for a local band and played badminton on Tuesdays. He lives with his wife; his children are grown up and staying away from home.

Peter identifies goals as wanting to be able to go back to work, play the guitar and regain IT skills. He has doubts whether he is being realistic and might not be able to return to exact pre-stroke status. Peter wants feedback from professionals that his performance is fitting to achieve his aims.

Peter moves on to analysing his occupational requirements at work and realises that he will not be able to use his computer as effectively as before at work.

Peter's motives in life are to enjoy life, achieve at work which he finds mentally stimulating, relax and feel peaceful with his music and maintain a social life.

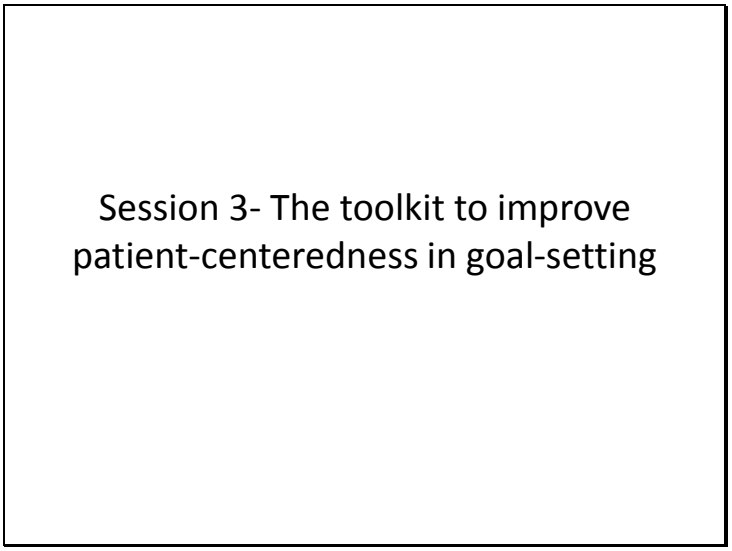
Peter feels mentally weak due to his cognitive deficits. Emotionally he is unable to accept his stroke as he does not have risk factors such as high blood pressure or cholesterol. He is also frustrated that he cannot function as normal and feels a loss of control as result of his current condition. He has doubts whether he is being realistic and might not be able to return to exact pre-stroke status.

Peter ignored early symptoms and drove in to work next day. He couldn't recognise anything abnormal in the early stages of stroke. Ever since the stroke he has slowly started to realise what the effects of his stroke were primarily because he was attempting to do routine activities which highlighted his issues.

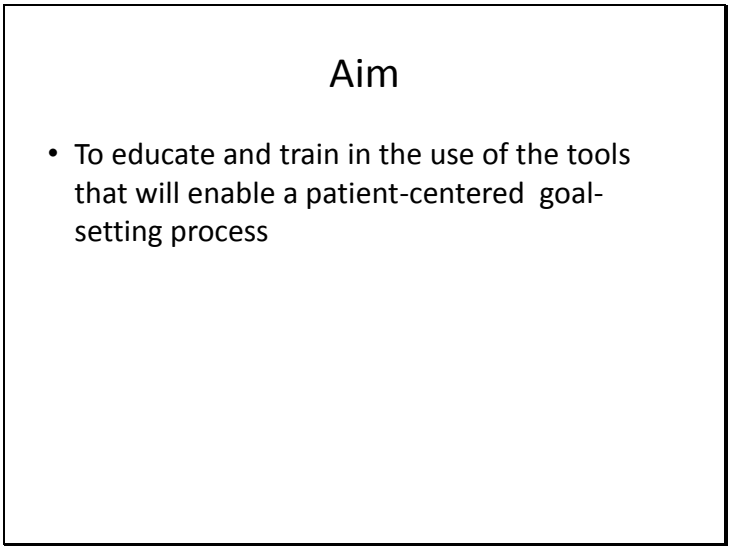
1. **Emotions**
2. **Understanding of motives**
3. **Biography**
4. **Subjective experience of illness and hospitalisation**
5. **Context and time sensitivity (Past and future)**
6. **Personal relevance of goals**

Appendix 5.3 e Slides for session 3- The toolkit to improve patient-centredness in GS

Slide 1

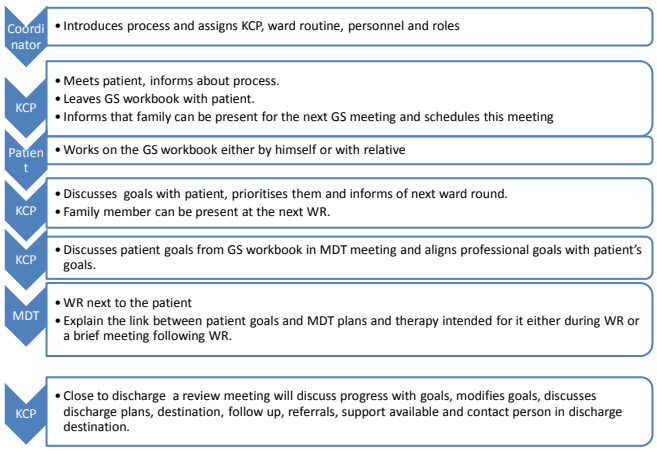


Slide 2



Slide 3

The pathway for the process



Slide 4

Patient-centered Ward Round (PCWR)

Preparation stage:

- For Staff: In MDT meeting following the goal discussion for a participant the KCP organises the time for WR involving all members caring for particular patient. It can be usually the same afternoon (since most members attend MDT) or the following afternoon.
- For Patient: In the meeting following the discussion of the goals filled in the GS workbook KCP explains that in the next ward round following the MDT meeting (i.e. the following Monday) the team will come to the patient to discuss any issues and patient's goals.
- Approximate time will be given.
- Patient can ask family member to be present with them during this rounds.

Slide 5

Review Meeting

Agenda for Review Meeting (few days prior to discharge if discharge date is known earlier or after a ten days –two weeks in the hospital) :
Pre review meeting:
KCP reminds patient about review meeting and asks patient to invite family member.
KCP also asks patient to reflect on his goals, progress, and consider the questions on his work book about discharge.
Review meeting:
To go through questions in work book and clarify any other issues raised by patient or family.

Appendix 5.4 a Responsibilities of key contact person (KW) for the GS process:

- Meet the patient as soon as possible after admission. Introduce self.

- Give generic information about the ward, professionals' roles and routines on the ward.

- Introduce the GS process, role of KW, patient's responsibilities and give and explain the GS workbook for exploring patient goals. Give at least 24-hrs to think about their goals and record in the GS workbook. Make appointment to meet family and patient to discuss goals.

- Discuss information recorded by patient in the GS document. Guide patient to set goals relevant to their personal their context. Prioritise their goals. Explore patient's perceptions about whether the goals suggested are realistic. Get further understanding of the patient's pre-stroke status, their needs, their motives and support available.

- Take GS document to next MDT and start discussion with the patient background information and discuss patient voiced goals. Break down life goals and relate them to the goals that each of the professionals has setup. After making this link, record it in the GS workbook.

- The next meeting with patient will involve negotiation; explain intermediate goals set by the team to the patient and clarify doubts. Ask patient to monitor whether he is progressing towards achieving his goals. Discuss discharge

options if it is evident from the MDT discussions. Give times of ward round and invite the family member to attend it.

- Act as patient advocate during ward rounds voicing his doubts to the team if patient does not speak for himself.

- Arrange for a review meeting and invite family to attend. Discuss progress from view of professionals in achieving goals. Also compare perceptions of patient regarding his progress with goals. Discuss discharge options, give information on destination of discharge, steps to point of discharge, support/contact after discharge and follow up arrangements.

- Reassuring, maintaining positive hope, using narratives are some strategies that can be employed to improve self efficacy during discussions.

- If possible move patient to a private area for discussions.

- Sit down every time you talk to the patient. Some patients need touch as a form of reassurance.

- **Appendix 5.4 b ..... Patient Information leaflet**

Rehabilitation after stroke

It is important for you to know that you have been admitted in a ward specialized in stroke care. Here we do our best to help your recovery to the maximum possible level. However this ward is a rehabilitation ward and so we request you to get involved so that we can work together to make you better.

Do you have any further questions about the information given here?

When you get admitted in the hospital the doctor, therapists and nurses will check your status and plan what can be done to improve your status. So they will set goals or targets to plan for your care and for your rehabilitation. A goal is something that you would hope to achieve over a period of time or a plan of action for future. Staff need to ask you what you would like to achieve as a result of your rehabilitation. So we would like to explain how we set goals for your rehabilitation.

CAN YOU HELP US IDENTIFY WHAT YOU WOULD LIKE TO ACHIEVE FOLLOWING YOUR STROKE?

Why do we need a process to set goals?

It has been recommended that this Goal Setting (GS) process must involve the patient so that care delivered is tailored to the particular patient's needs. But patients feel that they are not being asked or being ignored when decisions are made about their care and future. In order to involve patient better in deciding goals for rehabilitation, this modified process of setting goals has been developed.

- Our aims are to:
- Get maximum possible involvement of the patient in deciding rehabilitation plans
- Gain involvement of family
- Make sure all patient needs are understood at an individual level
- Build better communication channel between patient and the healthcare

What will happen?

Step 1: You will meet a Key Worker (KW) in the hospital. KW will help you to identify your goals. KW will discuss your needs and negotiate with the other staff on the team. They will be available to clarify doubts about your goals and give you information. KW will give you a GS workbook which has questions about yourself and needs that you have to think about.

Step 2: You can go through the GS book and can think about the questions. You can if you wish fill this document on your own or with your family member. Otherwise your KW will help you.

Step 3: Your KCP will meet you to discuss what your needs are and get to know you.

Step 4: KCP will take this to the health care team and discuss your needs and goals with the team in a weekly meeting.

Step 5: There will be a rounds in which staff will come to meet you and discuss your care. Your family member can be present to if they prefer to get involved and discuss your goals.

Step 6: There will be a second meeting your KCP who will explain things and give information about your care goals.

Step 7: Close to your discharge KCP will discuss the progress you have made and discharge plans.

Appendix 5.4 c The goal-setting work-book

Goal Setting Work Book

Patient details (sticker): Key contact person:

Date:

- We think it is important to take into consideration your needs and aspirations when we plan for your rehabilitation.
- We also recognise the importance of understanding your personal situation for effective planning.
- Therefore we would encourage you to contribute to this goal-setting process.
- This work book is being given to you to make you think of your needs, plan your care and decide on your goals for rehabilitation.
- We request you to think about the questions in your spare time and fill it in if possible.
- What you record here will help you, your carer and your key contact person (KCP) to raise issues and clarify doubts with the other team members.

- If you are unable to write then your KCP will fill it in for you.
- You can involve your family member/carer for filling in this workbook if you wish to.

First Meeting	1.	I would like my carer to be present at every possible step of this process of setting goals for my rehabilitation:	Yes/ No
	2.	Who in your family would like to be involved for communication and involvement in planning goals?	
	3.	Did you receive information about the ward routine and professionals on the ward?	Yes/ No

	4.	**Life before this hospital admission:**	
		a) Who do you live with?	
		b) What did you do in a normal week before your stroke?	
		c) What is your occupation?	
		d) What are your hobbies?	

	5.	**Current Situation:**	
		a) What are your current needs in the hospital?	
		b) What do you understand about your recovery?	
		c) What do you think are you current problems that will stop you from returning to your job or hobbies?	

	6.	**Future Goals:**	
		a) What would you like to achieve at the end of hospitalisation/rehabilitation?	
First meeting		b) Why are these goals important to you (Motives/Values)?	
		c) What skills do you think you need to rebuild to achieve the above goals?	

		d) What barriers do you think you need to overcome to achieve these goals?				
	7.	**Goal negotiation following discussion with MDT members:**				
Second meeting		**Patient goals**	**Needs identified based on prof Assessment**	**Professional Goals/ Discharge plans if any**	**Interventions proposed (linked to goals)**	**Understands & Consents**

		Notes:(any strong objections/who decided goals)				
	8.	**Goal review discussion**				
Third meeting		How do you think you are achieving or not achieving your goals?				

	9.	**Discharge and follow up**	
		a) What are your concerns about life after discharge/transfer?	
		b) Discharge destination information:	
		c) Steps in discharge process:	

		d) Follow up information:
		e) Any other issues raised by staff about patient care or clarifications required from patient?

		f) Goals achieved and revised goals that need to be carried on:

Please record any issues or doubts that you have in this page. You can ask the team members or your KCP when they come to talk to you.

Issues /Doubts	Clarifications/Information

Appendix 5.4 d Agenda for review meeting

Agenda for Review Meeting (few days prior to discharge if discharge date is known earlier or after a ten days –two weeks in the hospital) :

Pre review meeting:

KCP reminds patient about review meeting and asks patient to invite family member.

KCP also asks patient to reflect on his goals, progress, and consider the questions on his work book about discharge.

Review meeting:

To go through questions in work book and clarify any other issues raised by patient or family.

Appendix 6.1 a ..... Ethical Approval for Study two

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru

NISCHR
Gwasanaeth Moeseg Ymchwil | RES | Research Ethics Service

Dyfed Powys Research Ethics Committee
Postal address: PO Box 108
Building 1
St David's Park
Carmarthen SA31 3WY
(for sat nav SA31 3HB)

Telephone : 01267 225045
Fax : 01267 225226
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Website : www.nres.nhs.uk

Mrs Sheeba B Rosewilliam
Division of Nursing and Physiotherapy, School of Health and Population Sciences
College of Medical and Dental Sciences
No.52 Pritchatts Road
University of Birmingham
Birmingham
B15 2TT

23 August 2013

Dear Mrs Rosewilliam

Study title:	**Evaluation of a toolkit to improve patient-centeredness in goal-setting for patients with stroke.**
REC reference:	**13/WA/0275**
Protocol number:	**RG_13-179**
IRAS project ID:	**134450**

The Proportionate Review Sub-committee of the Dyfed Powys Research Ethics Committee reviewed the above application on 22 August 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Sue Byng, sue.byng@wales.nhs.uk.

Ethical opinion

The Committee were concerned that this patient group would generally be experiencing low mood and that distress during the interviews could be likely. However, the Committee felt that this sensitive area was within the researcher's professional remit although a more robust strategy should be put in place to direct a distressed patient to the appropriate person if necessary. This was particularly important as the patient's GP was not being informed of their participation in the study.

GIG NHS Bwrdd Iechyd Addysgu Powys Powys Teaching Health Board

Cynhelir Cydweithrediad Gwyddor Iechyd Academaidd y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd gan Fwrdd Addysgu Iechyd Powys

The National Institute for Social Care and Health Research Academic Health Science Collaboration is hosted by Powys Teaching Health Board

Ariennir gan Lywodraeth Cymru Funded by Welsh Government

University Hospitals Birmingham NHS
NHS Foundation Trust

Appendix 6.1 b Research and Development approval for Study two

The letter is redacted from the e-thesis for confidentiality protection.

Appendix 6.2 a Participant Information sheet for patients for Study two

Study information sheet for patients-Version no.1

Study title: Patient-centered goal-setting for stroke patients- an evaluative study

Why are we doing this study?

Patients prefer better involvement in their care especially when planning for their rehabilitation. This is in line with the government's health care policy that the care needs to be 'patient-centered' rather than doctor centered. 'Patient-centered' care is that which is tailored to individual patients and must consider their needs and expectations. Based on previous studies we understand that care is not totally patient-centered because we were not involving patients adequately in discussions about their care. When staff plan for patients' rehabilitation or care i.e. 'set goals or targets' patients were not being asked what they would like to achieve.

In 2011 patients and staff suggested ways of involving patients better in care planning and setting goals for their rehabilitation. Based on these ideas the current method in which we set goals has been modified to increase patient involvement. We need to evaluate whether this modified method of deciding goals for rehabilitation helps patients and staff.

This project is part of a PhD study. We invite you to take part in the project which will give you more opportunities to interact with staff, share your opinions and seek information regarding your rehabilitation. So please consider participation in this project and tell us your views about this at the end of your hospital stay.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before

you agree to take part. We thank you for the time and effort spent on considering participation in the study.

Who is doing the study?

This is a project done by the researchers from the University of Birmingham in collaboration with the University Hospitals Birmingham NHS foundation trust. Ms Rosewilliam is a Physiotherapist registered with the Health and Care Professions Council who teaches in the School of Health and Population Sciences at University of Birmingham and is carrying out this work as a part of a PhD program. Ms Carron Sintler a stroke consultant physiotherapist who works on the ward 411 is involved with this project.

Are you eligible to join the study?

All stroke patients who are medically stable and able to communicate fully after their stroke are eligible to take part in this study. It is important to note that participation is entirely voluntary and you are not obliged to support this study. The standard of care you receive or your legal rights will not be affected in any way if you do not wish to participate in this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason. A decision to withdraw at any time, will again not affect the standard of care.

What happens if you decide to participate?

If you decide to take part in the study you will be given more information about your role in setting goals for your rehabilitation. You will be asked to sign consent forms. Then you will meet your key contact person who will coordinate between yourself, your family and the staff to ensure your goals are recorded and worked towards.

You will be given a booklet which will guide you to think and plan for your rehabilitation. You can involve your family in any of these processes if you want. You will have opportunities to review your progress and discuss your discharge plans with your key contact person.

Close to discharge or following discharge you will either be asked to do an interview with the researcher which will last for about 45mins-1 hour. During the interview you will be asked about your care in the hospital especially the way in which your goals for rehabilitation were set, your involvement in care planning and whether you found it beneficial. Interviews will be arranged at a time convenient to you. If you find it tiring then the session can be broken up into two or more sessions. These interviews will be tape-recorded and transcribed into written text. All information will be made anonymous and stored securely in the researcher's office.

The researcher will also attend meetings where your goals are discussed, to observe the interaction between the various staff and to evaluate the process. She will look at your records to check if your needs/goals have been correctly identified, recorded and followed up.

Taking part in this study will not affect the care received in hospital for patients. If at any point you no longer want to take part, due to any reason, then the interview can be stopped at any stage. Again this will not affect your normal care that you receive in the hospital.

Are there any issues of confidentiality?

All your data will be stored on a secure computer. All personal data will be made unidentifiable before analysis. It will not be shared with any person other than the academic supervisors of the research. Published data will not include your personal details.

Why should I participate in the study?

Your contribution to this study is highly valued since it will help us to identify whether the modified process can enable patient centered planning for rehabilitation. With the knowledge that you share with us we hope to further refine the processes and improve the quality of care delivered for future patients with stroke.

Are there any risks?

Since this is a non interventional study there are no major risks associated with it. Sometimes the participant may become upset when discussing their condition. Reassurance and psychological support will be provided if needed. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. It is important to note that there are no special compensation packages available.

What happens at the end of the study?

If this modified process for involving patients in setting goals is found effective then it will be recommended for wider practice. The findings will be written up. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local trusts in the form of presentations and posters. If you would like to know the outcome of the study please feel free to contact the researcher involved and copies of reports will be sent to you. Anonymised data from this study will be used to support other similar research in the health field.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study. The research team wishes to thank you for giving your time in this time of stress whether you decide to participate in the study or otherwise. Thank you.

Contacts

1. **Sheeba B Rosewilliam**, School of health and population sciences, University of Birmingham, B15 2TT.
2. **Carron Sintler,** Consultant Physiotherapist for stroke services, Queen Elizabeth hospital, Birmingham.
3. Rachel Jones, Stroke coordinator, Ward 411, Queen Elizabeth hospital, Birmingham.
4. **Dr. Carolyn Roskell**, School of health and population sciences, University of Birmingham , B15 2TT,
5. **Dr. Anand Pandyan**, School of Health and rehabilitation, Keele University, Keele ST5 5 BG.

Appendix 6.2 b ... Participant Information sheet for staff for Study two

Study information sheet for staff -Version no.1

Study title: Patient-centered goal-setting for stroke patients- an evaluative study

Patients prefer better involvement in their care especially when planning for their rehabilitation. This is in line with the government's health care policy that the care needs to be 'patient-centered'. 'Patient-centered' care is that which is tailored to individual patients taking into consideration their needs and expectations. Previous studies showed us that we were not delivering patient-centered care because we were not involving patients adequately in discussions about their care.

Patients and staff suggested ways of involving patients better in care planning and setting goals for their rehabilitation. The current process has been modified based on these ideas. We need to evaluate whether this modified process of setting goals for rehabilitation can be implemented successfully in the current practice and find out the potential benefits for patients and staff. This project is part of a PhD study. We invite you to take part in the project which will give you more opportunities to interact with patients, adopt patient-centered practices and to share your opinions with the researcher. So please consider participation in evaluation of the modified process of goal-setting.

Please read the following material and decide if you would like to participate. You can discuss the information with others and the researcher involved before you agree to take part. We thank you for the time and effort spent on considering participation in the study.

Who is doing the study?

This is a project done by the researchers from the University of Birmingham in collaboration with the University Hospitals Birmingham NHS foundation trust. Ms Rosewilliam is a Physiotherapist registered with the Health and Care Professions Council who teaches in the School of Health and Population Sciences at University of Birmingham and is carrying out this work as a part of a PhD program. . Ms Carron Sintler a stroke consultant physiotherapist who works on the ward 411 is involved with this project.

Why this study?

The guidelines for health care professionals recommend that patients should be at the center of care especially when planning for their rehabilitation. It is believed that patient-centered care may lead to better participation and therefore better recovery. In this study we propose to modify practice in order to make it patient-centered and evaluate the feasibility and benefits of these changes.

Are you eligible to join the study?

This practice modification requires involvement of professionals who are keen to enable patient involvement during setting goals for the patient. All staff who care for stroke patients from the different professions are eligible to participate. It is important to note that participation in this study is entirely voluntary and you are not obliged to support this study. Even if you decide to take part you will have the right to change your mind and may withdraw at any time without giving any reason.

What happens if you decide to participate?

If you decide to take part in the study you will be given more information about your role in this modified process of care delivery. If you decide to take part in the study you will be asked to sign consent forms. You will be trained by the researcher and Principal investigator in the implementation of the modified goal-setting process. You will be requested to act as the key contact person for one particular patient for whom you will act as a patient advocate. You will also be guided in the use of the documentation and oriented in your role as the key contact person for a patient. You will have a checklist with reminders about your interaction with the patient before your meetings with the patient that will reinforce your therapeutic relationship with the patient.

You will be requested to participate in an interview with the researcher. During the interview you will be asked about caring for a stroke patient, their goal-setting and the issues and benefits of the modified process of goal-setting. The interview will take about 45-60 minutes. They will be scheduled at a time convenient to you. This interview will be tape-recorded and transcribed into written text. All information will be made anonymous and stored securely in the researcher's office.

In order to understand any feasibility issues with the process the researcher will observe meetings that involve setting and reviewing goals that involves the staff, patient and other members of the team. Further to discuss your experiences in this modified process you will be asked to participate in a focus group with other staff who piloted the process. This will take place on the ward at a time convenient to you and last for about an hour. Participation in this modified process is voluntary and taking part in this study will not affect staff performance reviews.

Are there any issues of confidentiality?

All your data will be stored on a secure computer. All personal data will be made unidentifiable before analysis. It will not be shared with any person other than the academic supervisors of the research. Published data will not include your personal details.

Why should I participate in the study?

Your contribution to this study is highly valued since it will determine the effectiveness of this patient-centered care process. Your views will help us to refine the process of goal-setting before it is recommended for future practice.

Are there any risks?

Since this is a non interventional study there are no major risks associated with it. Regardless of this, if you wish to complain, or if you have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. It is important to note that there are no special compensation packages available.

What happens at the end of the study?

The data collected will be analysed and findings written up. These findings and recommendations from these findings will be presented to the team and team leaders. These findings will then be published in health journals and presented to professionals at conferences. The findings will also be disseminated in the local trusts in the form of presentations and posters. Anonymised data from this study will be used to support other similar research in the health field.

Thank you

Thank you for taking time to read the information sheet and considering participation in the study. The research team wishes to thank you for giving your time whether you decide to participate in the study or otherwise. Thank you.

Contacts

1. **Sheeba B Rosewilliam**, School of health and population sciences, University of Birmingham, B15 2TT.

2. **Carron Sintler,** Consultant Physiotherapist for stroke services, Queen Elizabeth hospital, Birmingham.

3. **Rachel Jones**, Stroke coordinator, Ward 411, Queen Elizabeth hospital, Birmingham.

4. **Dr. Carolyn Roskell**, School of health and population sciences, University of Birmingham , B15 2TT,

5. **Dr. Anand Pandyan**, School of Health and rehabilitation, Keele University, Keele ST5 5 BG.

Appendix 6.3 a Consent form for patients for Study two

School of Health and Population Sciences
CONSENT FORM FOR PATIENT-Version No.1-Date 30.06.2013

Study title: Patient-centered goal-setting for stroke patients- an evaluative study

(Please tick either yes or no and add your initials in each box)

I confirm that I have read the information sheet about this study.

I confirm that I understand the above information sheet about this study. I confirm that I have had the opportunity to ask questions about this study to …….(Name of applicant contacting the subject) and that all my questions have been satisfactorily answered. Y/N

I understand that staff involved in the study may examine those sections of my medical notes that are relevant to my taking part in research. I give permission for these individuals to have access to my records Y/N

I understand that **my participation is voluntary** and that I am **free to withdraw at any time**, **without giving any reason**, without my medical care or legal rights being affected or compromised in any way. I am under no obligation to partake in the study. Y/N

I agree to take part in this study. Y/N
I agree to direct anonymous quotations being used. Y/N
I want to see any quotations before they are used. Y/N
I permit the use of anonymous data from this trial to support other research projects. Y/N

.....	.....	
(Patient name)	*(Patient signature)*	*(Date)*
.....	.....	
(Witness name)	*(Witness signature)*	*(Date)*
.....	.....	
(Researcher name)	(Researcher signature)	(Date)

Appendix 6.3 b Consent form for staff for Study two

UNIVERSITY OF BIRMINGHAM

School of Health and Population Sciences

CONSENT FORM FOR STAFF- Version-1

Study title: Patient-centered goal-setting for stroke patients- an evaluative study

(Please tick either yes or no and add your initials in each box)

I confirm that I have read the information sheet about this study.	Y/N
I confirm that I understand the above information sheet about this study. I confirm that I have had the opportunity to ask questions about this study to ……. (Name of applicant contacting the subject) and that all my questions have been satisfactorily answered.	
I understand that **my participation is voluntary** and that I am **free to withdraw at any time, without giving any reason**, without my legal rights being affected or compromised in any way. I am under no obligation to partake in the study.	Y/N
I agree to take part in this study.	Y/N
I agree to direct quotations being used.	Y/N
I want to see any quotations before they are used.	Y/N
I permit the use of anonymous data from this trial to support other research projects.	Y/N

.....	.....	
(Staff name)	*(Staff signature)*	*(Date)*
.....	.....	
(Researcher name)	(Researcher signature)	(Date)

Researchers: Mrs. S B Rosewilliam, School of Health and Population Sciences, University of Birmingham, Edgbaston, B15 2TT. Phone: 01214142910/07872955548
Clinical contact: Carron Sintler, Consultant physiotherapist for stroke services

Appendix 6.4 Case Study-1 for Introductory session

Ward rounds

Dr said hello and asked John how he was. John said he was getting better. Dr checked his pulse and said it was okay but he had a temperature. Dr checked his power and co-ordination and visual fields. Dr said his co-ordination was the problem. John said his speech was affected as well. Dr said it was expected with this type of stroke- both his speech and swallow would be affected. Dr said it will get better but slowly in such types of strokes. He asked about his feeding. John said he was not eating much due to his hernia and hiccups. Dr. asked if he was getting heart burns. Pt said not much but pain in the left lower aspect of tummy. Dr examined tummy and chest. Told his team to have repeat x-ray and to continue paracetamol. He said ENT will check his throat out. He told John that he will need MHH for rehab. John asked for how long to go before MHH?

Dr said maybe within the next week. John said that he has been in QE for 2 weeks. They smiled at him for this statement and said nice to meet him and left.

Team meeting

It was reported by the PT that John had improved in his nystagmus and dizziness. He had stood against the plinth on Thursday. Nurse co-ord reported that John's NG tube has been pulled out and he eats better. SALT felt that he had cognitive problems that are subtle. OT said there was nothing wrong and John seemed okay with them. SALT said he continues to eat and drink while he is coughing and when instructed not to do so he

agrees but still continues to do the same. OT said that she will check him again. She said that there were no issues noted during the functional tasks.

SALT said that John needs constant supervision during meal time. Dr said it will be better for him to have 600 calories than have nothing at all. He asked the team what the plan was. OT said they wanted to help him with washing and dressing. PT said they want to work on his sitting balance. He complains of abdominal pain in sitting though. But he had stood with 2 plinths on either side. He seemed to be getting frustrated these days. He has had a visit from the vestibular therapist and has been made to start vestibular exercises.

Dr said SALT can follow up on ENT since they have to work together on this patient. He asked them to monitor weight and he will go to subacute in 4-6 weeks.

PATIENT RECORDS					
MDT	MDT meeting	Discussion of patient status	Nursing –asks for toilet/All care PT: Dizziness limiting-will try again OT: Will assess SLT: NG /Dysphonic /IV fluids -Medical: Diagnosis Nursing –asks for toilet/All care PT: Improving sitting balance/awareness midline/tilt table practice- panic episode OT: W&D/Standing	Ongoing assessment OT/PT/NG feed/SALT review - SALT review/If not improving in swallowing next week for investigation PT-Increase tolerance to stand	MHH end of this week ? MHH next week

			needs assessment/ shaved by himself SLT: NG/single texture/Oral practice - Medical: abdominal pain/ pulled out NG tube Nursing –Transfers variable/helps with W&D PT: Tilt table/sitting work/stood with two near plinth OT: Cognition no issues noted with functional tasks SLT: Variable intake/? Cognition/ Mood: FRUSTRATED Medical: abdominal pain/ pulled out NG tube Nursing –needs help with W&D/NBM PT: Stood with standing frame/progressing well/aim: standing with two OT: Some Cognition issues → to fully assess SLT: NBM for 3 weeks till ENT review/ can be unrealistic Mood: FRUSTRATED	Try vestibular rehab approach/ Await ENT review/cognitive assessment/ change mattress to suit patient/ monitor weight/	PEG then MHH Home in approx 4 weeks MHH when ENT is sorted out

Appendix 6.5 Interview Question Guides for Study two

Patient Interviews-Question guide-Version No. 1- Date:

1. What are the patients Goals?	Prior Status	1. Before your stroke what would you do in a normal week?
	Present Status	2. Do you miss anything from what you have told me? 3. Why is it important to you? 4. In what ways has the stroke affected you? 5. Why? / What can/can't you do? 6. What are your needs in the hospital?
	Future Status	7. What would you like to be able to do following rehabilitation/ hospitalisation? 8. Why is it important? 9. How realistic do you feel this is given your stroke?
2. How central is the patient in goal setting process? Does the new process improve patient centeredness in goal setting?	Whether he/she feels central	10. Tell me about your understanding and experience of the goal-setting process? 11. Have you been consulted on your goals/ or on what you want to do in the future? 12. Who talked to you? What was decided? How was it decided? 13. Was there anything you needed to discuss and felt unable to? Why?
3. Feasibility issues.	Barriers	14. Did you experience any barriers to your participation in the goal-setting process? If so what were they? 15. What were the factors in the hospital/staff that limited you from participating in the process of setting goals?
	Facilitators and possible benefits	16. How do you think the process of goal-setting helped you? 17. Who/What factors encouraged/ motivated you to come forward and contribute to setting your goals?
	Strategies	18. How do you think we can improve this process of setting goals for rehabilitation?

Professional Interviews-Question guide –Version No.1

1. What are the patient's Goals?	Understanding of patient's stroke	1. Can you tell me how you came to know about patient X and his/her stroke? 2. Can you tell me about this patient's stroke? 3. What do you think are the needs of this patient? Is it important to know these and why?
	Present Status	4. What has been the impact of the stroke on this person's life? 5. What are you doing with this patient? Why?
	Future Status	6. What would you do expect this patient to do when he/she is better? 7. How did you decide on that? 8. What are you doing to work towards the above? 9. How do you plan for treatment and discharge for a patient?
2. How central is the patient in goal setting process? Does the new process improve patient centeredness in goal setting?	Whether patient is central	10. Have you consulted patient on their goals or on what they want to do in the future? 11. Who else did you talk to? What was decided? 12. How was it decided? 13. Was there anything you needed to discuss and was unable to? Why?

Appendix 6.6 Observation guide for Study two

General observations:

- Structure
- People
- Interactions
- Who talks?
- Decision making/power/ stance
- Verbatim conversations/ expressions/gestures
- Descriptions and dialogues

Observations for feasibility:

1. Compliance or adherence:

- Were any of the steps missed out?
- Who missed the steps?
- Why did they miss the steps?

2. Context:

- Line of management/ Hierarchy /champions for the cause?
- Management support?
- Existing capacity within team?
- Access to key staff for training? Space? Program materials? Evidence/science based information?
- Fit with previous programs?
- Staff workload implication? Prioritisation of activities?
- Process clash/interface interaction with other processes in care?
- Availability of information?
- Timing issues?
- Staff times?
- Access to patients over time?
- Incentives to accept change?
- Cultural relevance?

3. Delivery:

- Skills transfer within team?
- Collaboration of researcher with the staff in the set-up?
- Support for researcher on site?

4. Uptake:

- On-going leadership/championing?
- Team communication?
- Staff attitudes, behaviour in implementing?
- Flexibility in the use of the process?
- Logistics of organisation?
- Legal and ethical issues?
- Data management?

Appendix 6.7 Focus group Topic Guide for Study two

Focus group Topic Guide: Today we will be discussing the modified process of goal-setting and the tools used for this process. You will be asked to talk about the process in general, its usefulness, its limitations, challenges you faced in implementing the toolkit, and how we can make it better.

Warm Up Question	Understanding of Process and toolkit	1. What is your general understanding of why we have modified the goal-setting process? 2. Do you think the modified process has achieved the aims that it was set out for? Why do you think so?
Feasibility issues	Barriers	3. What dilemmas/problems did you face while implementing the various steps in this modified process? 4. What factors in the hospital/staff/patient made it hard for you to implement this modified process for setting goals? 5. Which specific tools were difficult to use and why?
	Facilitators	3. Who/What encouraged/motivated you to test this process? 4. What is your view of the training program for implementing goal-setting process? 5. What is your general opinion about how useful this toolkit was for making the process more patient-centered?
	Strategies	3. How do you think you can improve this process of patient-centred goal-setting for rehabilitation?

Appendix 6.8 Sample of data coding from Study two

	Codes	Categories
I: Thank you GS4. I want to ask you about your prior status, status before you had your stroke. Just tell me what would you do in a normal week before your stroke?		
GS4: Shopping hovering, gardening, job hunting	Household chores Gardening Job hunting	Pre-stroke status
I: Mmmm		
GS4: Mmm…Watching TV… Mmm… well	Entertainment	
I: It's quite a bit isn't it?		
GS4:Yeah		
I: Do you miss anything from what you have told me?		
GS4: I miss the walking.	Walking	
I: Ok Did you used to go for walks or something?		
GS4: I used to walk to the shops and back.	Shopping	
Ok. So you miss walking to the shops.		
GS4: Yeah		
I: Do you drive S?		
GS4: No		
I: OK so walking is your main …		
GS4: Yeah buses are so expensive	Conscious of expenses	Pat competency/ attributes
I: OK you always prefer to walk. Are the shops close by or do you have to walk a long distance?		
GS4: They are about half a mile away		
I: How often do you go to the shops then?	Walking everyday	
GS4: Everyday		
I: Every day Ok		
GS4: More or less		
I: So why is it, of all the things you've told me, you miss walking the most isn't it?		
GS4: It's how I get out and about	Social activity	
I: Ha	HOV-Socialising	HOV
GS4: I miss the you know meeting		

people in the shops and library I: Ok. How often did you go to the library? GS4: Nearly every day. I: OK GS4: Off on Wednesdays because it is closed I: Alright…wow GS4: For computers….cause I haven't got a computer at home I: So for your job hunting you used the library did you? GS4: You get nine hours free a week. I: OK (Interviewer takes tissues to give patient to wipe his dribble) GS4: I do read a bit as well. Never used to read I: Pardon me? GS4: I never used to be a reader but now I've been reading a lot. I: Ok you have picked up this habit of reading is it? GS4: Mmm… I: What sort of books do you read? GS4: Biographies. I: Mmm GS4: Crime I: Crime? Mmm. So what do you reckon? How has the stroke affected you? GS4: Can't do everyday things. I: Mmm… GS4: Can't think my personality has changed I: Ok. Your personality is the same but you think can't do your physical activities. GS4: Yeah it's just everyday things, like eating and going to the toilet I: Ok. In any other way has it affected you? Long pause… GS4: No. I: Alright. You have already told me what things you can't do. What things can you do now actually? GS4: What can I do? I: Mmm GS4: I can read a bit and I can …I've got a bit more out going…	Social activity Library visits Use of computers Makes it evident that money is short Job Hunting Conscious of expenses Reading Pat per Disablement No change in personality Eating Toileting Disablement Social skills	Pre-stroke status Pat competency/ attributes Pre-stroke status Pat per Effects

Appendix 6.9 Sample of summary of data from documents from Study two

	[redacted]	
Name of the document	MDT weekly sheet (Day 4)	Prac. Prof-Prof Coll.
Authorship	Signed by Consultant Physio	
Structure	**General:** Pat details; Condition details; each row dedicated for Medical, nursing (continence), PT (mobility and transfers) OT (washing and dressing and cognition), SLT (communication/diet, fluids & swallow), Mood, BI, Social/domestic; social work referrals; community referrals; Discharge destination; estimated date; Follow up plans Person filling it in. **Relevance to PCGS: MDT agreed goals: Patient wants to return home/work/DIY/gardening and socialising/ Physio follow up in OPD at QEH/can go home/offer review for previous depression and possible cause of stroke.** **Discharge destination:** **Estimated discharge date: 24.03.14**	Aspects of PCC- Scope for Multi-professional input Chall to PCC: restricting scope of professionals Scope for Focus on: Physical function Cognitive function Communication/diet Behavioural /social Aspects of PCC Referrals (SW/ community) Follow up plans Prof per goals Return home Gardening, socialising, follow up plans/ review previous psychological problem.
Content	How Why What: Professionals have reported on the patient	Prac.Prof-Assess. Profession specific report

	status from their perspective Medical: Lysis on 20.3.14/assume infarct/ Sciatica/resolving rt weakness/ Nursing : PT for MRI/unclear cause/?stroke as CT is normal/?functional overlay PT: Independent on ward/mobility not quite back to normal OT: Goals are LT see below SALT: Pt complains of wordfinding difficulty/ NDF speech NAD Diet: Psychologist: Depression previously/was off work before/Mood NAD today. When: 24.03.14	Prac. Sys-Care Deliv Intervention Belief-pat. rec. Investigation Questioning cause of stroke Prof per-condn. assess. Mobility/independence Views on GS Aspects of PCC LT goals Pt complaints recorded Psychological issues discussed.
Position of document	After continuation sheets	
Frequency of use		
Components of PCGS		
MDT input-documented by one person. Assessment, management, issues documented. Goals not specified. Profession –specific care discussed. More patient-centred as it is holistic and psychological goals have been discussed. Not clear the purpose of use.		

Appendix 6.10 Spread of cases across the continuum of different levels of congruence- Study two

Dimension: Ensuring all aspects of their health problems are attended to (Holistic)	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant	Comparison with Spread in study 1
Biological	12345				Not too different
Psychological	125	4	3		Some improvement
Social factors	15	2	34		Not too different
Participation	135	24			Good improvement
Environmental		1		2345	Not different
Economic		5	4	123	Some difference
Health promotion	2	54	3	1	Some difference
Carer/family	23	15		4	Good improvement
Transition	123	45			Good improvement
leisure	2	134		5	Good improvement
Dimension: Establishing a therapeutic relationship	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant	Comparison with Spread in study 1
Clinicians' attitudes	15	234			Good improvement
Maintain positive hope		45	23	1	Not much
Bonding	2345	1			Very good improvement
Prof respect	12345				Very good improvement
Congruence	1235	4			Some improvement
Dimension: Identifying and catering to a patient's individual needs (Individualistic)	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant	Comparison with Spread in study 1
Biography	12345				Not too different
Subjective experience	45	3	12		Some improvement
Understanding	253	14			Very good

psychological world					improvement
Emotions	1	245	3		Not too different
Context and time sensitivity	125	34			Not too different
Personal relevance	1235	4			Very good improvement

Empowering and sharing responsibility	Reasonably Good Congruence	Partial Congruence	Incongruent	Not relevant	Comparison with Spread in study 1
Active problem solving	13	245			Good improvement
Self-efficacy			1345	2	No change
Informational control	2345	1			Good improvement
Executional autonomy			2	1345	No difference
Decisional autonomy	1	32		45	Good improvement
Active participation	1345	2			Good improvement
Multi directional ongoing information exchange	12345				Good improvement
Patient as expert	135	24			Good improvement
Patient autonomy	2345	1			Not much
Strengthening problem solving	1345	2			Good improvement
Habilitation			45	123	Some change

Appendix 6.11 Factors Influencing Goal-setting Sample of Clinicians' data from Study two

WHAT FACTORS INFLUENCED GOAL-SETTING IN THIS SETTING? CLINICIAN DATA					
	Beliefs, attributes	Practice	Experience of Goal-setting	Patient attributes	Challenges
GS1	Focus on medical aspect by doctor Exploring pre-stroke status Doctor values therapists input Professional believes patient's recovery is good and fast Motives were about comprehensive care, long-term planning, safety KW is new to setting KW is experienced in GS previously Motivated, led by patient's views	Doctor delivered information on recovery and discharge Flexibility in discharge plans Profession specific assessment, investigations, information discussed and observed OT considered risks at home and home adaptations Interventions included referrals to psychologist, balance training, advice on phased return to work, pacing, liaising with employer Profession specific assessment and	GS considered complex Follows assessment/ as a part of assessment Goals discussed for GS1 in MDT were around anxiety related to return to work Earlier discharge based on patient's expressed desire Follow up plans in OPD KW Perceived longstanding needs and immediate needs KW considered effects of hospitalisation as well as stroke Considered pre-stroke status, roles, psychosocial needs, environmental factors Patient's goals perceived as independence Focus on identified issues Routinely KW said he involved the patient and carers Explored patient preferences Set goals relevant to pre-stroke status and roles Follow up of goals	Ability to state clear goals	Ambiguous diagnosis Limited insight early on Unable to predict recovery Lack of review can make goals to be lost Limited family involvement Institutional time frames Inability to address short term/LT goals Severity of impairment

		goals. OT goals recorded were about mobility, transfers, stair assessment and discharge with ESD. Collaborative therapy records were used by PT, OT and SALT. Plans for discharge despite patient not being back to baseline and discussions regarding follow up with patient were recorded.	Breaking down goals Goal determinant was level of activity in hospital, current status, ongoing recovery Compensatory goals if potential was weak Improved insight with time and therapy input Review in GS for realistic, appropriate and goal achievement Setting slightly challenging goals Patient determined level of difficulty Individualistic approach for a psychological boost Flexibility in GS process (variation in time, intensity) MDT agreed goals were about patient's choice to go home early, DIY, gardening, socialising, follow up for balance deficits in the OPD and review for psychological issues. OT had recorded study input as doing interview, recording goals in workbook with patient, discussing goals with MDT, feedback to patient from meeting and follow up on goals after discharge (not a part of study). Goals were recorded as physio in the community for balance and psychologist input.		
GS2	Professional believed patient	Investigations for	KW perceived limited needs in the	Keeps issues to	Professional's

	was recovering well.	arterial occlusion done. Surgery done to remove occlusion. Continuity of care for this patient by the same nurse. Patient was informed of remnant problem. Provided psychological support, nursing care for personal needs, Understood patient's normal behaviour Involved family in care KW considered carer's concern Wife was a communication channel Level of independence at discharge and therapists judgement of ability/ restrictions would help determine goals. Flexibility in plans	hospital which included post-surgical nursing care, assistance with mobility, pain relief, He was independent in personal care Considered pre-stroke status, roles, psychological needs, fear, need for support for anxiety, informational needs about medication, follow up KW considered effects of hospitalisation and effects on family KW perceived his goals were to reach pre-stroke status, household chores, baking, church activities, wanted to reduce his commitments Identified restrictions in driving Wife involved in GS KW believed he will achieve all his goals Liaised with team during acute complication Exploring patient outcomes, pre-stroke status, restrictions MDT input Collaboration with therapists KW appreciated patient's contribution to goals Encouraged and prompted Opportunity to record queries Explained steps in the process Gave feedback from MDT meetings Goals discussed in MDT were return	himself Did not ask for help Not make a fuss Nice Comfortable to work with Patient approachability Pleasant family	unfamiliarity with personality limitations in knowledge Workload Not aware of current status Unpredictable recovery time Unpredictable prognosis Unexpected complication Deterioration in condition Duty rota Interruptions to discussions Multiple demands on time Busy workload Team dynamics in MDT meeting

		due to complications and outcome of investigation Leader's satisfaction with plans Doctor offered opportunity for clarifications Flexibility in working with patients Doctor focussed on discussing medical aspects in MDT Flexibility in planning and doctor agreed to plans for follow up of goals. Therapy record showed assessment following surgery with no issues, SALT record of voice issues and plans to review.	home, baking, driving, and participating in church activities. Discussed patient's concern of re-stroking in MDT meeting. Goal set to refer to stroke association for further information. Plans made for review of goals in stroke clinic. Staff other than KW suggested the strategy for review of goals. Gave advice on goals. KW gave further information related to treatment. Family involved in GS discussions. Reassured patient about looking for cause. Discussed logistics of discharge with family. Weekly MDT record showed patient agreed goals were recorded as to return home and continue his hobbies. Goals were also recorded as refer to stroke association for gaining further information and follow up at stroke clinic.		

Appendix 6.12 Factors Influencing Goal-setting- Sample of Patients' data from Study two

Influence of implementation of toolkit –patients' perspectives						
	Beliefs, attributes	Experience	Goal-setting	Professional and system influences	Challenges	Refinement
GS1	Patient believed she had a quick and full recovery. Positive, takes time to bond Her motives were gain control over life, independence Motivated Proactive in filling in documentation Active participation in discussions Keen to go home	Patient felt satisfied with care in hospital, appreciated the service. She perceived continual support Feels safer and more confident.	She perceived her goals were to reach her pre-stroke status. She perceived that she could reach her goal. Severity of disability determined goals. She recalled KW discussing goals Setting goals help to cope, gives a reality check, acceptance strategy and helps to adapt to change. She felt that she had been represented in MDT. Involvement in decision making.	Professionals offered information Approachability of staff. Spent time with patient to share information Professional who was not her KW facilitated plans for goal achievement. Professional prioritised psychological need.	Inadequate time to get to know and talk to KW due to short stay. Lack of privacy to discuss personal issues.	Private space for discussions Variable input for others.

			Discussion of options Identification of psychological and social needs Consideration of previous health influences Specific goals set for psychosocial needs.			
GS2	Patient's motives were attachment to family, enjoyment in helping, looking out for elders, futuristic outlook, independent, not wanting to bother others or family, health outlook and his dignity. He perceived age as a barrier to return to pre-stroke status. He believed early frustration was settling in. He prioritised recovery of health before taking on	Patient perceived his needs were met in the hospital and he was satisfied with care Patient appreciation of professional input for patient care. Perceived an open channel of communication and was	Patient believed activities had been put on hold He perceived his goals as wanting to do cooking, household chores, helping others, DIY, resume church activities , improve fitness, He wanted to be realistic and reduce commitments He believed it is early to miss out on activities to realise his goals. Expected that	He perceived he had a good rapport with staff Comfortable environment Approachability of staff	He was unaware of strategies put in place.	

	harder goals. He was an understanding and helpful person, keen He had positive hope and believed he would recover with time. Wife perceived he was frustrated, aspired for independence and refused help Patient was proactive and had filled in the workbook.	satisfied with discussions.	realisation would happen in near future. He suggested GS set strategies for rehabilitation such as mobility, helped coping, provided support for adaptation and determined personal help required. Perceived open communication channel			

Appendix 6.13 Feasibility of application of toolkit for Patient-centred Goal-setting – Sample data from Study two

Feasibility of the process				
Staff FG	Facilitators	Challenges/limitations	Refinement	Perceived effects
	Delegation of role Conversation starters Extracting themes Easy to administer Need for structure Motivation for change Closeness to nurses Facilitator role Not totally new process Toolkit: Helpful case studies Awareness of chall. within routine GS Behavioural checklist Reminder of behaviour Real case studies Related to cases Recorded questions Time effective Proactive family Wife as communication channel	Stand-alone input for GS Evolving diagnosis Backing off goals Not integrated in to system Quick discharge/short stay Not changed culture Not integrated in to system Time factor for routine integration Interruption of routine role Distraction of normal responsibility Continuity in communication Limited handover Urgent responses to family Shifting rapport to different KW Limited knowledge of patient from handover by KW Communication difficult on paper	To tackle limitations Time to integrate Flexibility in process Fit in stroke pathway Fly availability matched with KW Scope of fly availability Preparing for GS Breaking down broad goals Shaping patient goals Preparation for GS Keyworker/ discussion with professional Continuity in KW role Time efficient GS in therapy session Difficult with other therapies Overload during therapy sessions	Preparing for GS Awareness of patient ideas: Discussions improved awareness Regained confidence in practice Improved patient-centredness Recorded questions Patient confidence about information Patient awareness of goals Foresee barriers at home Spending time with patient Gained understanding of patient Understanding patient needs Patient reassurance Awareness of community support Awareness of care continuum Consultants keen on PCGS Keyworker role Therapist leading case discussion Shift from doctors leading MDT Doctors' awareness GS's importance Wider effect on other patients Therapist leading case discussion

		Perceived time length for full roll out Logistical challenges Multiple patient in process MDT clash with day off Specifying appointments Busy workload Patient's routines Fly visiting after work Lack of continuity to sub-acute Losing faith in process Non-optimal relationship with subacute staff Repetition of GS Rebuilding relationship Part time role on ward Fly involvement Emergency needs Limited rehabilitation needs Generic goals/broad goals Long term goals Unrealistic goals Difficulty breaking up goal Follow up after discharge Tool not helpful to shape goals Interrupting PT role Setting timed goals Hard to visualise LT goals	Complete in one block One review of GS Document discussed in MDT Documentation for patient goals Scope of fly availability Exclusion criteria Record of feelings or outcomes Accessible GS record Electronic record Quality of life Need based goals Need for non-rehab goals Medical goals Quality of life goal Quality of end of life Individualistic approach Integrate in to conversation Pre-stroke status Family involvement Communication tools Talking maps Not open structured Too closed for patient	Shift from doctors leading MDT Therapist leading case discussion Reflection on practice Effect on other patients Focus on goals Reflection on practice Effect on other patients Focus on goals Improved clinical reasoning Opportunity to participate in wider care Opportunity to participate in GS Opportunity to participate in GS Improving service standards Reflection on practice Reflection on practice Patients' satisfaction Reflection on practice Preparation for GS Preparation for GS Clarified carer's queries

		Not fit for patients with communication difficulties Communication problems Patients get spoken for Medical model Different family interests Complex patients Goals given to patients Communication difficulties Perceived time length Specifying appointments Interruption of routine role Busy workload Continuity of KW role Eligibility to involve Complexity (speech) Complexity (psychological) Severity of illness Emergency needs Waiting for recovery Poor prognosis Complexity of tools Unpredictable prognosis Delirious patient	opinion Non-specific key worker Sharing KW responsibility Sharing KW responsibility Exploring history Adapting the questions Routine assessment Adapting questions Integrate questions	
GS1	Enthusiastic/ motivated staff Independence in implementation KW identified alternate strategy to achieve aims	Staff in the facilitator's role not available on ward due to other responsibilities. Limited staff representation in ward rounds Precedence of clinical need	Needs a facilitator on the ward to start process with patient and link patient to KW	Patient appreciation Early discharge GS draws out issues Identifies issues not picked by other assessments Time allocated to focus on goals

	of the process Flexible working Friendliness Clarifying patient's responses Keen KW Derived themes from patient input in the workbook to set goals Workbook helped identify goals Short time for GS1 to fill in workbook	Review cycle incomplete Complex words in questions Perceived it would be time consuming with patients with cognitive problems	Potential proxy responders Thirty minutes would be appropriate	Focussed process Concise Specific Feedback from team members
GS2	Key worker discussions Friendly atmosphere KW attributes-Friendly Jovial Patient's active participation Rapport between patient and professional KW identified alternate strategy to achieve aims of the process (delegated MDT discussion due to day off)	Time lapse since process was unhelpful to recollect process Lost documentation did not help patient to remember his discussions. Limited staff representation in ward rounds Delays in appointments with families Issues arising with family involvement Busy workload	Expand to bigger crowd and further evaluation NEED FOR FACILITATOR	Comforting Reassurance Satisfaction Informing Less anxiety Well informed No anxiety Comforted KW perceived patient benefitted from research participation. Specific goals set. Patient appreciated time and information given by KW.

Appendix 6.14 Sample Illustration of the logical derivation of key themes and subthemes-Study two

Feasibility of Application -Practicality